EXPLORING THE EXPERIENCES OF MENTAL HEALTH PROFESSIONALS TOWARDS PEOPLE WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS IN SINGAPORE

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Abstract

Background:

Mental health problems of people with intellectual disabilities can negatively affect the willingness of healthcare professionals to work with them and their family carers to support them. There has as yet not been any research to understand the experiences of different stakeholders providing care and treatment to this population in Singapore.

Aims:

This thesis used a qualitative approach to explore 1) the experiences of mental health professionals working with this population, 2) the experiences of family carers and service users about the specialist mental health service and their mental health experiences in Singapore.

Methods:

Five groups were identified. Individual interviews or focus group discussions were conducted with mainstream and specialist mental health professionals; family carers of people with intellectual disabilities; inpatient and outpatient service users. Thematic and interpretative phenomenological analysis were used to analyse the participants' quotes.

Results:

Mainstream mental health professionals reported feelings of uncertainty when working with people with intellectual disabilities and required additional training and knowledge to increase their confidence managing the mental health needs of this population. Specialist mental health professionals reported initial fears when starting out and became more

confident with increased experience over time. They were more likely to interact with people with intellectual disabilities and involved their family carers during treatment to improve their health outcomes. Family carers found it challenging to deal with the mental health and behaviour problems of their relatives and were satisfied with the services provided by specialist mental health professionals. Outpatient service users had more opportunities to participate in the community and received more family support than inpatient service users. Both groups of service users desired an increased choice and autonomy over their lives, however their views were neglected as mental health professionals often took into consideration the views of their family carers during the treatment process.

Conclusions:

The findings of the current research provide an increased understanding of the lived experiences of different stakeholders and how the culture of Singapore has an impact on the provision of mental health services and outcomes of people with intellectual disabilities. Recommendations are made for service delivery and for improving the clinical practice of healthcare professionals working with people with intellectual disabilities and mental health problems.

Dedication

This thesis is dedicated to my late father who taught me to always pursue knowledge with passion and zeal. May you be proud of my achievements and thank you for your guidance

"There you saw how the Lord your God carried you, as a father carries his son, all the way you went until you reached this place." Deuteronomy 1:31

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Table of Contents

LIST OF APPENDICES ..... **X**

LIST OF ABBREVIATIONS ..... **XI**

LIST OF TABLES ..... **XIII**

LIST OF FIGURES ..... **XIV**

DEFINITIONS OF KEY TERMINOLOGY ..... **XV**

CHAPTER 1: INTRODUCTION **21**

BACKGROUND 21

Challenges in providing MH services for people with ID *22*

AIMS OF RESEARCH THESIS 32

PART I: LITERATURE REVIEW **35**

CHAPTER 2: A SYSTEMATIC REVIEW OF THE ATTITUDES AND PERCEPTIONS OF HEALTHCARE PROFESSIONALS TOWARDS PEOPLE WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS **36**

INTRODUCTION 36

Aim of the review *37*

METHOD 38

Literature Search *38*

Search Strategies *39*

Quality Assessment Tool *41*

Data Extraction *42*

RESULTS 43

Descriptive Overview of the studies *43*

Healthcare professionals' attitudes and perceptions *61*

Training, knowledge and competency *61*

Vulnerability, segregation and empowerment *63*

Emotional reactions *64*

Impact of attitudes and perceptions on service delivery *65*

DISCUSSION 67

Limitations *72*

Clinical implications *74*

CONCLUSIONS 75

CHAPTER 3: EXPLORING THE EXPERIENCES OF HEALTHCARE PROFESSIONALS PROVIDING SERVICES TO ADULTS WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS – A QUALITATIVE REVIEW AND META SYNTHESIS **77**

INTRODUCTION 77

Key findings from the quantitative review *78*

Aim of the review *79*

METHOD 80
Literature Search *80*
Search Strategy *81*
Quality Assessment Tool *82*
Extraction of data for meta-synthesis *83*
RESULTS 84
Descriptive characteristics of the studies *85*
Meta-Synthesis Findings *101*
Main theme 1: Understanding the person with ID and mental health problems *102*
Main theme 2: Relational Interaction *106*
Main theme 3: Organisational factors *111*
DISCUSSION 116
Strengths and limitations of the research reviewed *121*
CONCLUSIONS 123
Summary of findings from both literature reviews *124*

PART II: EMPIRICAL STUDIES 126

CHAPTER 4: STUDY 1 – EXPLORING THE EXPERIENCES OF MAINSTREAM MENTAL HEALTH PROFESSIONALS WORKING WITH PEOPLE WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS 127

INTRODUCTION 127
METHOD 129
Setting *129*
Interview Schedule *130*
Ethics *132*
Procedure *132*
Using Thematic Analysis (TA) *133*
Trustworthiness in analysis *136*
RESULTS 138
Main theme 1: Working with people with ID *139*
Main theme 2: Perception towards people with ID *143*
Main theme 3: Ideal characteristics of healthcare professionals *147*
Main theme 4: Service recommendations *149*
DISCUSSION 154
Implications of findings *161*
CONCLUSIONS 161

CHAPTER 5: STUDY 2 – EXPLORING THE EXPERIENCES OF SPECIALIST MENTAL HEALTH PROFESSIONALS WORKING WITH PEOPLE WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS 163

INTRODUCTION 163
METHOD 166
Setting *166*
Participants *166*

Interview Schedule *167*
Procedure *167*
Analysis *167*
RESULTS 169
Main theme 1: Role of specialist mental health professionals *170*
Main theme 2: Ensuring continuity of care *176*
Main theme 3: Disempowerment of service users *182*
Main theme 4: Improving clinical practice *187*
DISCUSSION 190
Implications of findings *197*
CONCLUSIONS 199

CHAPTER 6: STUDY 3 – FAMILY CARERS' EXPERIENCES OF PROVIDING CARE AND VIEWS OF SERVICES FOR THEIR ADULT RELATIVE WITH INTELLECTUAL DISABILITIES AND MENTAL HEALTH PROBLEMS 201

INTRODUCTION 201
METHOD 202
Participants *202*
Interview Schedule *204*
Procedure *205*
Data Analysis *207*
RESULTS 213
Master Theme 1: Making sense of behaviour *214*
Master theme 2: Some services are better than others *219*
Master theme 3: Public reaction - "If they make a noise, people are scared" *225*
Master theme 4: Worries and hopes for the future *228*
DISCUSSION 233
Implications *241*
CONCLUSIONS 243

CHAPTER 7: STUDY 4 - WHAT ARE THE EXPERIENCES OF SERVICE USERS RECEIVING INPATIENT SPECIALIST MENTAL HEALTH INTELLECTUAL DISABILITY SERVICE IN SINGAPORE? 245

INTRODUCTION 245
METHOD 248
Participants *248*
Interview Schedule *250*
Procedure *251*
Data Analysis *252*
RESULTS 255
Master theme 1: Awareness of mental health problems – "Because I a bit… My brain…craziness…" *256*
Master theme 2: Yearn for a life outside the ward – "I want to go home" *258*
Master theme 3: Interacting with other people *259*

Master theme 4: Finding purpose *262*
DISCUSSION 263
Limitations *268*
Implications *268*
CONCLUSIONS 270

CHAPTER 8: STUDY 5 - WHAT ARE THE EXPERIENCES OF SERVICE USERS RECEIVING OUTPATIENT SPECIALIST MENTAL HEALTH INTELLECTUAL DISABILITY SERVICE IN SINGAPORE? 271

INTRODUCTION 271
METHOD 272
Participants *272*
Interview Schedule *273*
Procedure *273*
Data Analysis *274*
RESULTS 275
Master theme 1: Sense of self - "I feel angry with myself, I blame myself" *276*
Master theme 2: People who matter to me *277*
Master theme 3: Choice and autonomy - "Just respect me" *282*
Master theme 4: Hopes and dreams *283*
DISCUSSION 284
Implications *288*
CONCLUSIONS 289

PART III: BRINGING EVERYTHING TOGETHER 290

CHAPTER 9: OVERALL DISCUSSION 291

COMPARISON OF FINDINGS 291
HOW DO HEALTHCARE PROFESSIONALS IN SINGAPORE DESCRIBE THEIR EXPERIENCES WORKING WITH PEOPLE WITH ID AND MH PROBLEMS? 297
WHAT ARE THE IMPLICATIONS OF THE CURRENT FINDINGS FOR THE SPECIALIST MH ID SERVICE? 301
Addressing stigma *302*
Early access and detection of MH problems *302*
Recruiting suitable specialised healthcare professionals *303*
Increasing training and competency *304*
Working with people with ID *305*
RECOMMENDATIONS FOR FUTURE RESEARCH 307
SUMMARY 308

REFERENCES 311

List of appendices

Appendix 1: Information Sheet and Informed Consent Form (Mental Health Professionals) (Links to Chapter 4 and 5) 365
Appendix 2: Interview Schedule (Mental Health Professionals) (Links to Chapter 4 and 5) 371
Appendix 3: Participant Demographic Sheet (Mental Health Professionals) (Links to Chapter 4 and 5) 373
Appendix 4: Example of a worked interview transcript (MMHP) (Links to Chapter 4) 374
Appendix 5: Table of themes for all MMHPs (Links to Chapter 4) 382
Appendix 6: Example of a worked interview transcript (SMHP) (Links to Chapter 5) 389
Appendix 7: Table of themes for all SMHPs (Links to Chapter 5) 398
Appendix 8: Participant Invitation Letter (Links to Chapter 4 to 8) 407
Appendix 9: Participant Information Sheet and Informed Consent Form (Caregivers) (Links to Chapter 6) 408
Appendix 10: Participant Demographic Sheet (Family Carers) (Links to Chapter 6) 414
Appendix 11: Interview Schedule for Family Carers (Links to Chapter 6) 415
Appendix 12: Example of a worked interview transcript (FC) (Links to Chapter 6) 417
Appendix 13: Table of themes for all FCs (Links to Chapter 6) 427
Appendix 14: Simplified Information Sheet and Informed Consent Form (Links to Chapter 7 and 8) 433
Appendix 15: Assessment of capacity to consent (Links to Chapter 7 and 8) 450
Appendix 16: Activity for service users during interviews or focus groups (Links to Chapter 7 and 8) 451
Appendix 17: Pilot Study with the people with ID in the UK (Links to Chapter 7 and 8) 457
Appendix 18: Example of a worked interview transcript (ISU) (Links to Chapter 7) 458
Appendix 19: Example of activity with ISU (Links to Chapter 7) 464
Appendix 20: Table of themes for ISU (Links to Chapter 7) 466
Appendix 21: Example of a worked interview transcript (OSU) (Links to Chapter 8) 468
Appendix 22: Example of activity with OSU (Links to Chapter 8) 479
Appendix 23: Table of themes for OSU (Links to Chapter 8) 481
Appendix 24: University of Birmingham Ethics Approval Letter 484
Appendix 25: Research Approval Letter from Singapore 485
Appendix 26: Personal reflections (Links to Chapter 4 to 8) 488

List of Abbreviations

ADL	Activities of Daily Living
ANDS	Adult Neurodevelopmental Service
ASD	Autism Spectrum Disorder
ATTID	Attitudes towards Intellectual Disability
CBT	Cognitive Behaviour Therapy
CLAS	Community Living Attitude Scale
FBA	Functional Behaviour Analysis
FC	Family Carer
HCP	Healthcare Professional
ID	Intellectual Disabilities
IMH	Institute of Mental Health
IPA	Interpretative Phenomenological Analysis
ISU	Inpatient Service User
MH	Mental Health
MHCP	Mainstream Healthcare Professional
MHP	Mental Health Professional
MMHP	Mainstream Mental Health Professional
ND	Neurodevelopmental Disorders
OSU	Outpatient Service User
PBS	Positive Behaviour Support
SHCP	Specialist Healthcare Professional
SMHP	Specialist Mental Health Professional

SRV	Social Role Valorization
SU	Service User
TA	Thematic Analysis
UK	United Kingdom
USA	United States of America

List of Tables

CHAPTER 2
TABLE 2.1: INCLUSION AND EXCLUSION CRITERIA FOR QUANTITATIVE REVIEW 38
TABLE 2.2: LIST OF SEARCH TERMS FOR LITERATURE REVIEW 39
TABLE 2.3: SUMMARY OF QUANTITATIVE STUDIES INCLUDED IN THE REVIEW 44
TABLE 2.4: QUALITY ASSESSMENT OF QUANTITATIVE STUDIES 59

CHAPTER 3
TABLE 3.1: INCLUSION AND EXCLUSION CRITERIA FOR QUALITATIVE REVIEW 80
TABLE 3.2: SEVEN STAGES OF META-ETHNOGRAPHY FROM ATKINS ET AL. (2008) 84
TABLE 3.3: SUMMARY OF QUALITATIVE STUDIES INCLUDED IN THE REVIEW 86
TABLE 3.4: QUALITY ASSESSMENT OF QUALITATIVE REVIEWS 99
TABLE 3.5: SYNTHESIS OF THEMES ON HCPS' EXPERIENCES OF WORKING WITH PEOPLE WITH ID AND MH PROBLEMS 101

CHAPTER 4
TABLE 4.1: DEMOGRAPHICS OF MAINSTREAM MENTAL HEALTH PROFESSIONALS 130
TABLE 4.2: INTERVIEW SCHEDULE 131
TABLE 4.3: DESCRIPTION OF THEMATIC ANALYSIS (BRAUN & CLARKE, 2006) 135
TABLE 4.4: MAIN THEMES, SUB-THEMES AND THE PARTICIPANTS THAT CONTRIBUTED TO EACH SUB-THEME 139

CHAPTER 5
TABLE 5.1: DEMOGRAPHICS OF SPECIALIST MENTAL HEALTH PROFESSIONALS 166
TABLE 5.2: MAIN THEMES, SUB-THEMES AND THE PARTICIPANTS THAT CONTRIBUTED TO EACH SUB-THEME 169

CHAPTER 6
TABLE 6.1: DEMOGRAPHICS OF FAMILY CARERS 203
TABLE 6.2: INTERVIEW SCHEDULE OF FAMILY CARERS 205
TABLE 6.3: STAGES OF IPA FROM SMITH ET AL. (2009) 208
TABLE 6.4: MASTER THEMES, SUB THEMES AND THE PARTICIPANTS THAT CONTRIBUTED TO EACH SUB THEME 213

CHAPTER 7
TABLE 7.1: DEMOGRAPHICS OF INPATIENT SERVICE USERS 249
TABLE 7.2: INTERVIEW SCHEDULE OF SUS 251
TABLE 7.3: MASTER THEMES, SUB THEMES AND THE PARTICIPANTS THAT CONTRIBUTED TO EACH SUB THEME 256

CHAPTER 8
TABLE 8.1: DEMOGRAPHICS OF OUTPATIENT SERVICE USERS 273
TABLE 8.2: MASTER THEMES, SUB THEMES AND THE PARTICIPANTS THAT CONTRIBUTED TO EACH SUB THEME 275

List of Figures

CHAPTER 2

FIGURE 2.1: FLOW DIAGRAM OF THE SYSTEMATIC LITERATURE REVIEW 41

CHAPTER 3

FIGURE 3.1: FLOW DIAGRAM OF THE QUALITATIVE REVIEW.....82

Definitions of key terminology

This section outlines the different key definitions/terminology used throughout the research thesis.

Neurodevelopmental disorders (ND)

This term refers to a group of disorders in the growth and development of the brain and central nervous system are impaired before the onset of adulthood (American Psychiatric Association, 2013). The range of developmental deficits varies from specific limitations of learning, control of executive functioning to global impairments in social skills, communications, movement, intelligence or memory ability. The developmental deficits are caused by structural, for example problems with body parts, such as brain, heart or functional birth defects. The birth defects can result from a combination of genetic or environmental factors. Both Intellectual Disability and Autism Spectrum Disorder are classified under this umbrella term and are discussed in the below section:

Intellectual / Learning disabilities (ID)

These terms are often used interchangeably and may be defined differently depending on the country and the context that it is being used in. In North America and Singapore, where this research thesis is focused on, Intellectual Disabilities (ID) is the favoured term to use among healthcare professionals. On the other hand, the term Learning Disabilities is used instead in the United Kingdom (UK) because of the paradigm shift to focus on the individuals' capabilities instead of emphasizing on the intellectual deficits or impairment.

Regardless of which terms are used, the following three criteria must be met as defined according to the British Psychological Society (The British Psychological Society, 2000):

1. Significant deficits in intellectual functioning, for example in abstract reasoning, comprehending new or complex information, impairment in problem solving and difficulties in academic learning or learning from past experiences. This is usually measured by clinical assessment and individualised psychometric assessments and confirmed by Intelligence Quotient (IQ) scores of less than 70.
2. Significant deficits in adaptive or social functioning, for example impairment in participating in one or more activities of daily life, such as communication, social participation, and independent living across multiple environments.
3. These intellectual and adaptive deficits are acquired during the developmental period before the age of 18.

The classification of severity (i.e mild, moderate and severe) is dependent upon the severity of the intellectual and adaptive impairment.

The term ID will be used throughout the thesis instead of the term Learning Disabilities. The term Learning Disabilities used in UK is not be confused or interchangeably used with the term Learning Disabilities used in North America and Singapore. In those countries, learning disabilities is an umbrella term to denote neurologically-based processing problems that can interfere the individual in acquiring learning basic skills such as reading, writing or manipulating arithmetic problems. When these problems are not addressed during the early school years, they may affect the individual's higher level processing skills such as executive functioning in planning, organization or abstract reasoning, as well as attention and memory impairment (Learning Disabilities

Association of America). Examples of specific learning disabilities include dyslexia and dyscalculia. These individuals usually have normal or above average intelligence and show a gap between their potential and actual achievement. This thesis will not cover this group of individuals.

Autism Spectrum Disorder (ASD)

People with ID may present with co-morbid neurodevelopmental disorder, such as Autism Spectrum Disorder (ASD). ASD is characterised by American Psychiatric Association (American Psychiatric Association, 2013) with the following criteria:

1. Persistent deficits in social communication and social interaction across multiple environments. Examples range from failure to initiate and respond to social interactions, such as engaging in appropriate back-and-forth conversations with others, failure to understand nonverbal communication behaviours such as gestures and facial expressions, failure to develop meaningful relationships and adjusting behaviour or sharing interests with peers in different social context.
2. Restricted or repetitive motor movements or having highly fixated interests that the individuals are strongly attached or preoccupied with that becomes difficult to adjust or change. In addition, the individual may have difficulties adapting to sensory input from their environment which could have significant distress to the individual.
3. These deficits and restricted patterns of behaviours or interests occur during the developmental period before the age of 18 and contribute to significant impairment across multiple environments, such as home and school, which affects their current functioning.

Research has not found any specific causes that contribute to autism. It is most likely due to a combination of genetic and environmental factors. There is no current cure for autism, though individuals with autism may live independently. In some cases, individuals with autism may have accompanying intellectual and adaptive/social impairment.

Healthcare Professional (HCP)

The role of healthcare professional (HCP) is to provide quality evidence-based healthcare treatments to diagnose, treat and prevent physical and mental health conditions in the population (World Health Organization, 2013). They are highly skilled workers with a professional qualification (often a university-level degree) and practise in varying specialisations. They work in various settings such as in the hospital, primary health centres and social services.

The term Mental Health Professional (MHP) used in the empirical studies of the research thesis (Chapters 4 to 8) refers to those providing mental health services in a tertiary hospital setting. The term Specialist Mental Health Professional (SMHP) in Chapter 5 refers to those providing specialist mental health services for people with neurodevelopmental disorders, such as ID and ASD. Examples of healthcare professionals working in a mental health setting are psychiatrists, psychologists, nurses, social workers and occupational therapists. This group of healthcare professionals may receive additional postgraduate training with relevant clinical experience in mental health in addition to their basic professional qualifications.

Mental Health Problems

There are varying definitions of mental health. According to the World Health Organization (2004), it refers to a psychological state of well-being where the individual can deal with normal life stressors, and can participate in his or her own community through working productively and having social relationships. The definition does not merely indicate an absence of mental health problems but also refers to the individual using his or her abilities to contribute to the society. Jahoda (1958) further categorises mental health into three domains which are 1) individuals reaching their full potential, 2) understanding their stressors within their environment and 3) a sense of autonomy, such as able to take active steps to deal the stressors through problem solving.

Research literature indicates a vast number of conceptualisations for the term mental health problems and there is no consensus on how to define this term for people with ID (Bouras et al., 1998). For the purpose of the thesis, mental health problems are defined as the emotional difficulties that people with ID experience which can include mood and anxiety disorders, substance misuse and addictions, psychoses and behavioural problems such as sexually inappropriate behaviour.

There has been a debate whether challenging or problem behaviours such as aggressive behaviours should be included under the definition of mental health problems (Costello et al., 2007). Emerson (2001) defined challenging behaviour as “culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities” (p. 3) and believe that it should not be used as a diagnostic criterion to identify mental health

problems but to understand the needs of the individual receiving community services. However, people with ID with low mood are found to engage in challenging behaviours (Hayes et al., 2011) and to access mental health services. Therefore, the term mental health problems used in the research thesis will include people with ID who display challenging behaviours and are receiving mental health services for treatment.

Chapter 1: Introduction

Background

People with Intellectual Disabilities (ID) are estimated to make up 1 to 3% of the general population (Harris, 2006; Maulik et al., 2011) and a high percentage of this group will develop some form of mental health (MH) and/or behavioural problems during adulthood. (Deb et al., 2001; McKenzie et al., 2016). Young adults with ID are likely to experience increased levels of anxiety and depression when transitioning from adolescence to adulthood that may affect their adjustment and well-being (Gobrial & Raghavan, 2012; Young-Southward et al., 2017). A number of countries have investigated the prevalence rate of MH problems of people with ID, for example, a prevalence rate of 32% of people with ID having co-morbid psychiatric disorders was found in Australia (Morgan et al., 2008). Another study indicated that 23.8% of adults with ID have some form of MH problems such as affective disorders and psychoses in Japan (Shimoyama et al., 2018). Despite the higher prevalence of MH problems of people with ID (Hatton et al., 2015), they are in receipt of fewer resources where only a relatively small proportion of them (21%) are known to MH and community services (Emerson et al., 2011). Additionally, Shimoyama et al. (2018) found that only a minority of them seek psychological services. Poor accessibility is said to be one of the barriers that could account for the low utilisation of MH services for people with ID (Alborz et al., 2005; Leyin, 2011; Sin et al., 2010) despite guidelines and legislature in the United Kingdom (UK) to encourage accessibility of MH services for people with ID (Department of Health, 2001).

Challenges in providing MH services for people with ID

The general health outcomes of people with ID remain significantly worse when compared to the general population because their MH needs are often unrecognised which may impact on prognosis, recovery and life expectancy (Cooper et al., 2007; Young-Southward et al., 2017). Research findings suggest systemic issues in MH services can have an impact on the accessibility of MH services for this group including poor training and competency to work with people with ID among mental health professionals (MHPs), a lack of understanding to recognise the manifestations of MH symptoms in adults with ID by carers and healthcare professionals (HCPs) (Costello et al., 2007; Moss et al., 1997); and a lack of coordination in referrals to appropriate agencies for management and treatment of MH symptoms (Trollor, 2014). Some psychiatric conditions such as schizophrenia may appear earlier in adults with ID which, if left untreated or not properly managed, result in greater impact and distress to themselves and family carers (FCs), highlighting the importance of early access to MH services for this population (Morgan et al., 2008).

Lack of MH treatment can affect self-image and self-esteem which prevent people from leading a 'normal' life and result in them being excluded from their communities (Morisse et al., 2013). Multiple studies have revealed the impact of MH problems on caregivers where they experience high levels of stress and co-morbid psychiatric symptoms due to dealing with a high care burden (Dawson et al., 2016; Maes et al., 2003; Waite et al., 2017). Some caregivers lack knowledge regarding the resources available to address their relative's MH problems at an early stage (Ali et al., 2013) and delays in MH service response (Scior & Longo, 2005) can result in crisis hospital admission when carers can no longer manage.

The attitudes of MHPs towards people with ID are likely to impact the kind of treatment and quality of services received, which can affect their outcomes (Rose, 2011). The experiences of carers indicate stigmatising attitudes in MHPs that discourage them to seek MH service for their relatives with ID (Ali et al., 2013). Likewise, carers perceived that their relatives are discriminated and poorly treated by MHPs when they receive mainstream MH treatment (Donner et al., 2010; Longo & Scior, 2004; Scior & Longo, 2005).

There are differences in attitudes between MHPs working in mainstream versus specialist settings which indicate more favourable attitudes and positive emotions among MHPs working in specialist settings (Rose et al., 2012; Rose et al., 2007). Carers in the UK found that they could discuss information relevant to their relative with specialist staff who were more open to involving carers during the treatment process (Scior & Longo, 2005). The experiences of service users indicate that mainstream MH professionals are not equipped to deal with the specific needs of adults with neurodevelopmental disorders (ND), such as those with Autism Spectrum Disorders (ASD) and/or ID (Crane et al., 2019; Donner et al., 2010; Lunsky & Gracey, 2009). Diagnostic overshadowing can happen in people with ID when HCPs fail to acknowledge behavioural problems as possible MH problems and instead consider them to be part of the neurodevelopmental diagnoses (Reiss et al., 1982). For example, Mason and Scior (2004) found that psychiatrists and psychologists fail to identify MH problems of people with ID, supporting previous findings by Jopp and Keys (2001) that indicate diagnostic overshadowing may influence clinical judgement of HCPs and treatment of people with ID. Another example is that the clinicians may ignore and minimise the MH problems when carrying out assessment that may be explained by the availability and representative heuristics.

A challenge remains for mainstream MH services to meet the MH needs of people with ID in non-western countries (Kwok & Chui, 2008; Shimoyama et al., 2018; Wei et al., 2012). Kwok and Chui (2008) found that Asian countries offer varying standards of psychiatric care to people with ID, often using treatment approaches such as restraints, psychotropic medication and behavioural interventions. Wei et al. (2012) notes that mainstream MH programmes exclude people with ID in Singapore and they receive unsatisfactory mainstream MH treatment that results in frequent hospital admissions without any significant improvement. Little is known about MHPs' experiences in Singapore or any South East Asia country of providing MH services to people with ID and there remains a lack of understanding of how their experiences influence their attitudes and perceptions. Additionally, there are no studies involving people with ID and their carers to explore their experiences of receiving MH services in those countries.

The Context of Singapore

Singapore is a small island-city republic state that comprises of 718 square kilometres. It is a former British colony located in the Southeast Asia region, which is situated at the southern tip of peninsular Malaysia. Since becoming independent in 1965, the population has grown to more than 5 million people, with the majority of ethnic Chinese (75%) origin and including ethnic minorities of Malays (14%), Tamil (9%) and other smaller ethnic groups such as Eurasians (of European and Asian descent; Department of Statistics, 2019). The population of Singapore is described as multi-culturally diverse with an equal prominence placed on different cultures and religions, and the adoption of four official languages – Mandarin, Malay, Tamil and English. Following independence, Singapore transformed her

economy to a metropolitan global city with one of the highest Gross Domestic Product (GDP) ratings in the world.

There are many unique characteristics about Singapore compared to other South East Asia or Asian countries. The majority of the population use English as their first spoken language. Many of the political, social and healthcare institutions have evolved from past colonial British systems with a Western perspective. As such, Singapore shares similarities with the British healthcare system using modern Western medicine as a treatment approach to address the general healthcare and MH needs of the population. Singaporeans have easy access to healthcare and education facilities that result in better subjective well-being, higher quality of life and a longer life expectancy when compared to other countries in the region (Chan & Kamala Devi, 2012; Leow et al., 2013). With the advancement in economic progress following independence, Singaporeans are becoming more affluent, technologically advanced and exposed to Western values of individualism. Strong economic success has led Singapore to become a developed country that shares many similarities with the Western developed countries and societies.

Nevertheless, Singapore has its own distinct culture as it is also influenced by non-western philosophies due to its proximity to China and other South East Asia countries. Singaporeans endorse social cohesiveness, belonginess to families and communities that look after one another (Kee, 2004). Many commonly held values are based on Chinese Confucian principles that emphasise the importance of hierarchical structures and relationships as a way of order in a society. (Foo et al., 2006). Hence, Singaporeans have learned to defer respect to people in authority position of power, display conformity towards societal norms and place less emphasis on individualistic needs and values. This provides a juxtaposition of ‘East meets

West' identity among Singaporeans who have adopted features of collectivistic values in a metropolitan state.

Another unique socio-characteristic of Singapore culture is the concept of meritocracy which is engrained in Singaporeans' values and beliefs systems, where socioeconomic mobility can be achieved based on merit, ability and working hard to attain success regardless of one's background or ethnicity. The principle of meritocracy has led Singaporeans to define success as having a good education, a high income and career prospects (Foo et al., 2006). Singapore's economic success and political stability are attributed to this emphasis on meritocracy but have contributed to the perception among Singaporeans that their society has become too competitive and materialistic, thus creating anxiety and fear of not keeping up with other people's progress and 'losing out' (Wong, 2018). Some segments of the population are indeed left behind, marginalised and struggle to achieve in these competitive conditions (Teo, 2019). Despite the rapid rise of Singapore becoming a developed country, it has one of the highest income inequalities (Lee & Morris, 2016).

Singapore Healthcare Services

The healthcare system in Singapore purports to ensure that general health services remains affordable and accessible for its citizens. The primary healthcare services comprise of 20 polyclinics which are funded by the government and 1,700 private general practitioner clinics (Singapore Ministry of Health, n.d) which form the bedrock of the healthcare system. Singaporeans pay subsidised rates when they receive medical treatment at the polyclinics and the physicians will refer them for tertiary general health or MH services when their medical condition become too complex and difficult to manage.

Tertiary general health services are provided by a total of eight public hospitals, a women's and children's hospital and a psychiatry hospital (Singapore Ministry of Health, n.d). These hospitals provide inpatient and specialist outpatient services as well as 24-hour emergency departments. They are partially funded by the government and Singaporeans are expected to pay for medical treatments with subsidies and financial assistance provided if necessary. Additionally, there are eight privately funded hospitals where Singaporeans pay the full cost of medical treatment without subsidies.

Healthcare Coverage

Singaporeans can access subsidised treatment for both inpatient and outpatient services in the public healthcare system. The healthcare coverage uses a mixed financing model where a single medical treatment episode can be covered by various government schemes (Lai, 2015).

MediSave is the compulsory national medical savings scheme; working individuals put aside a certain portion of their income to pay for their own personal or their immediate family members' inpatient hospitalisation treatment and certain outpatient expenses, such as chronic disease management and some psychiatric conditions (i.e. affective disorders and schizophrenia) (Singapore Ministry of Health, n.d). Singaporeans are required to pay a portion of their treatment fees after subsidies either with their own cash or withdrawal from their MediSave account. Non-pharmacological outpatient treatments and general health services in the community are not covered under this medical scheme.

MediShield Life (Singapore Ministry of Health, n.d) is a basic compulsory health insurance plan that Singaporeans pay the annual premiums using their MediSave account. This insurance scheme helps to pay for large hospital bills and some costly outpatient treatments,

such as chemotherapy and dialysis and helps Singaporean to pay less cash from their MediSave account or out of their own pocket. Singaporeans can also purchase private insurance plans to supplement this basic health insurance which then can be used to pay for private treatment in the public or private hospitals.

Lastly, Singaporeans who face financial difficulties paying their remaining bills after receiving subsidies and using other means of payment including MediSave, MediShield and cash can tap into MediFund. This is an endowment fund set up by the Singapore government and a referral to a social worker is required for means testing before Singaporeans are allowed to use this fund. (Singapore Ministry of Health, n.d).

The Singapore healthcare system has evolved over the years and treatment charges are based on the individual's and their family's ability to pay to ensure that everyone, regardless of their financial situation, can access healthcare services when needed.

Mental health services in Singapore

Singapore has only one tertiary psychiatric hospital, The Institute of Mental Health (IMH), that provides acute tertiary MH services. Other general hospitals in Singapore have dedicated psychiatric departments that provide psychiatric and psychological services to meet the increasing MH needs of Singaporeans. In the past, people were often treated at the tertiary and general hospitals where they would be admitted for long periods of inpatient treatment and rehabilitation. However more recently, there is an emerging shift initiated by the Singapore Ministry of Health towards expanding MH community-based services, provided in government polyclinics or private general practitioner clinics, hence increasing the accessibility to care and reducing the demand for institutionalised care (Kua & Rathi, 2019). High levels of resources are currently being directed towards increasing the

competency of healthcare professionals (HCPs) and support staff working in the community to provide community-based interventions and case management for the general population.

Specialist MH ID service in Singapore

Singapore does not have official census data on the prevalence rate of people with ID. However, the Singapore government ministry has conducted a national survey using self-reported measures which indicates that the prevalence rate of people with disabilities, including those with sensory, physical, cognitive and neurodevelopmental impairment, is 2.1% in the population group of 0-17 years old, 3.4% in the population group of 18-49 years old and a higher prevalence rate of 13.3% in the older population of those 50 years and above (Singapore Ministry of Social and Family Development, 2017). Significant proportion in these three groups may have co-morbid cognitive or neurodevelopmental disabilities for example Autism Spectrum Disorder (ASD) or Down Syndrome. There are no official statistics on the prevalence of people with cognitive or neurodevelopmental disabilities who have co-morbid MH problems.

Although there have been no studies in Singapore to evaluate the provision of MH services to people with ID or investigate the attitudes of HCPs towards people with ID, there is an obvious need to develop a specialist MH ID service as the current mainstream MH services and programmes in the community exclude them. HCPs working in general and psychiatric hospitals have recently become aware of severe service gaps and find it difficult to collaborate with the social service sectors (Wei et al., 2012). Wei et al. (2012) argues that the hospitals in Singapore have become a “dumping ground” (p. 431) for people with ID. The deterioration of MH problems in people with ID can contribute to a significant increase in

care burden among FCs which may leave them feeling overwhelmed and unable to continue taking care of their family members with ID (Dawson et al., 2016; Kim, 2017). When they become too difficult to manage in the community, this leads to frequent hospital admission or long duration of inpatient stay.

Singapore is chosen as the research setting for this thesis as it has established a specialist MH ID service since 2011 to meet the specific MH needs of people with ID. IMH established the Adult Neurodevelopmental Service (ANDS) that provides inpatient and outpatient specialist MH service for adults with ID and/or ASD in Southeast Asia (Institute of Mental Health, 2012). The eligibility criteria for this service are: 1) Adults between 19 and 64 years old, 2) Adults with ND including ID and ASD and 3) Presence of co-occurring MH and behavioural problems that do not improve after seeking mainstream MH services. People with ID and/or ASD are referred to ANDS from mainstream healthcare services in the hospital as well as polyclinics located in the community.

The psychiatrists in the ANDS have specialist qualifications in psychiatry of ID and work with a multidisciplinary team that is comprised of psychologists, nurses, occupational therapists, case managers and speech therapists. During the assessment phase, the specialist mental health professionals seek to understand the person with ID better through direct interviews and observations with FCs in the outpatient clinic located in the hospital. The diagnosis and treatment plans are shared with the FCs and the person with ID and/or ASD. A total of 272 adult people with neurodevelopmental disorders (ND) received specialist MH services between January 2015 to December 2016 (Moon et al., 2020). These authors found that the typical profile of these service users (SUs) was Chinese males with mild levels of cognitive impairment, having received up to primary school education, and currently unemployed and

living in nursing or residential homes. A smaller number of these SUs lived with family members and attended day care at activity centres where they received additional skills training.

Specialist MH services are also offered in inpatient settings for people with ID. Specialist MHPs engage with family carers to encourage them to actively participate in the treatment and the care plan. In situations where the family carer refuses to take the person back home after their MH symptoms have been resolved, the person with ID will be transferred to a long-stay hospital ward awaiting step-down transition care to a residential home. The long-stay hospital wards are 36-40 bedded dormitories with patients of the same gender. Previously, the activities in the hospital ward were scheduled for people with ID without considering their views. However, more recently attempts have been made to allow SUs to choose activities based on their interests.

The recent adoption of a specialist MH ID model in a Singapore setting with its own unique cultural identity makes a compelling case to explore the views and experiences of different stakeholders. It remains unknown whether this western service model can be successfully replicated in Singapore or whether any cultural adaptations need to be considered. Hence, it would a good start to explore the functioning of this new service by understanding the experiences of MHPs working with people with ID and MH problems in mainstream as well as specialist settings. This may increase the level of knowledge in the field of ID in Singapore and inform further ways of improving the service.

Aims of Research Thesis

This research thesis sets out to achieve several aims. The first aim is to explore the experiences of mental health professionals (MHP) who provide mainstream and specialist MH services to adults with ID in Singapore. The second aim is to understand the issues faced by caregivers when they take care of their relatives with an ID and their experiences of MH services delivered to their relatives. The final aim is to gain an insight into the experiences of service users (i.e. people with ID), how they cope with their MH problems and to obtain their feedback regarding the MH services that they receive from MHPs. This thesis therefore primarily involves the search for common themes found in data derived from a number of different stakeholder groups to achieve an increased understanding of how MH services for people with ID in Singapore are perceived.

The research is comprised of five separate studies which have each targeted five different homogeneous participant groups. The first group is made up of mainstream mental health professionals (MMHPs) and the second group is specialist mental health professionals (SMHPs). The MMHPs had significantly less contact with adults with ID and a lower level of training, knowledge and skills in this area as compared to the SMHPs. The third group of participants consists of family carers (FCs) who were main caregivers with significant caregiving responsibility and a high level of contact with their relatives with ID. The fourth group of participants are adult service users with ID who were receiving inpatient specialist MH ID treatment in the hospital (ISUs) and the final group os made up of adult SUs with ID receiving outpatient specialist MH ID services in a tertiary hospital (OSUs).

There are shortcomings in using traditional quantitative approaches in the field of disability studies. The findings from quantitative data obtained from large sample sizes may not

contribute to the understanding of the experiences of people with disabilities, especially with regard to their views and opinions about the services they received and the challenges they experience in the community (Avramidis & Smith, 1999). This research adopts an interpretative research paradigm to understand how the realities of different stakeholders are socially constructed and influenced by the cultural context of a Singapore specialist MH service.

The five empirical studies in this thesis focus on acquiring a detailed understanding from within a Singaporean cultural context. The studies involving MHPs use thematic analysis which is a focused approach to identify issues relevant to the research topic and involve less interpretation of the data. Interpretative Phenomenological Analysis (IPA) is less structured and used for studies involving FCs and SUs which allow them more opportunities to explore their experiences. With this approach, the participants are guided by the researcher to construct their own socially subjective realities and make sense of their experiences.

By recording and systematically analysing the experiences and views of all of these five stakeholder groups, this research aims to provide a detailed insight into how MH services are delivered to people with ID in Singapore which may inform recommendations to improve the existing services.

A number of objectives were set and are described in the following chapters:

Part 1 consists of two literature reviews. Chapter 2 is a systematic literature review of quantitative studies examining the attitudes and perceptions of HCPs working with people with ID and MH problems. Chapter 3 is a meta-synthesis review that reviews qualitative studies exploring the experiences of HCPs providing services or care to people with ID and MH problems. The findings of both literature reviews summarise the current knowledge

about attitudes and experiences of HCPs working with people with ID and MH problems. Additionally, the reviews analyse the quality of the selected studies and explore the common themes and findings found in these studies. This provides a summary of the quantitative and qualitative evidence before describing the findings of the current research that was set in Singapore.

Part 2 consists of five empirical studies conducted in Singapore to explore the experiences of different stakeholders involved in the MH services for people with ID. Chapter 4 and 5 explore the perspectives and experiences of MMHPs and SMHPs using face-to-face individual semi-structured interviews. Chapter 6 describes the experiences and perspectives of FCs, their caregiving responsibilities and how they understand their relative's MH problems. Chapter 7 and 8 describe the experiences of ISUs and OSUs, how they understand their own MH problems and how they experience MH ID services.

In Part 3, Chapter 9 provides an overall discussion of the findings of the empirical studies and makes recommendations for improving specialist services in Singapore and for further research.

PART I: Literature Review

Chapter 2: A systematic review of the attitudes and perceptions of healthcare professionals towards people with intellectual disabilities and mental health problems

Introduction

People with ID are poorly integrated in MH services (Ervin et al., 2014) and the provision of MH services remains undeveloped when compared to services for the general population (Bhaumik et al., 2008). There have been calls to reform MH services and improve access for people with ID (Trollor, 2014). Alborz et al. (2005) found that general practitioners are often the first point of contact for people with ID to receive general health services but they are ill-equipped to manage the MH needs and do not make appropriate referrals to specialist MH ID services, suggesting lack of knowledge and skills to identify MH problems of people with ID.

Trollor (2014) recommends accessible mainstream as well as specialist MH services for people with ID. A review (Whittle et al., 2018) indicates that barriers to MH services are related to deficits in knowledge and stigmatizing attitudes in HCPs, highlighting the need to improve their attitudes and perceptions of this population. There has also been an increased emphasis on providing staff training in the MH needs of people with ID to HCPs, MHPs and support workers (Woodward & Halls, 2009) which can improve attitudes, as well as skills and knowledge (Rose et al., 2013).

There is a limited amount of research conducted to understand the attitudes and perceptions of HCPs working with people having ID with MH and/or behavioural problems. Most of the studies and reviews to date are focused on attitudes of HCPs providing general health services to people with ID only. Only a review by Werner and Stawski (2012) explored the knowledge of ID and MH, attitudes and training of professional staff. However, the review did not define the professional background of the sample sufficiently and the selected studies mainly comprised psychiatrists without including samples from other professional groups. Another review (Pelleboer-Gunnink et al., 2017) also found stigmatizing attitudes in HCPs providing general and psychiatric services to people with ID. However, only nine studies included in the review focused on psychiatrists or HCPs working with people with ID and MH problems, and eight out of the 30 studies identified in the review were conducted more than 10-20 years ago when there was less awareness of the rights of people with ID and little training available for HCPs.

Identifying the attitudes and perceptions of HCPs working with people with ID and MH problems would aid in understanding whether they impact on the MH service delivery and of confidence in working with this population. Moreover, it would be useful to understand the training needs of HCPs to aid in the development of training programmes and supervision so as to improve their competency and thus the MH treatment received by people with ID.

Aim of the review

The review aims to investigate the attitudes of HCPs towards people with ID and MH problems. The review examines the findings from the literature in order to understand how HCPs perceive this specific population, their knowledge and competency in providing

services or interacting with them, and the impact of their attitudes on service delivery and training needs.

Method

Literature Search

The inclusion and exclusion criteria were developed after conducting a preliminary search. The objective of the search was to identify peer-reviewed studies that explore or evaluate attitudes and perceptions of HCPs providing services for people with ID and MH problems.

Table 2.1 shows the inclusion and exclusion criteria that were applied to the remaining studies after screening out duplicates. Definitions of HCPs and MH problems are explained in the *Definitions of key terminology* section of the research thesis (page xv). The remaining studies were assessed based on the title and the abstract obtained through the e-library search at University of Birmingham.

Table 2.1: Inclusion and exclusion criteria for quantitative review

Inclusion Criteria	Exclusion Criteria
Sample consists of HCPs including medical staff, nurses, therapists, psychologists and social workers	Focus on efficacy of specific interventions delivered to people with ID and mental health problems by HCPs
Must examine the attitudes or perceptions of HCPs who work with adults with ID and MH problems	Explore efficacy of training programmes that influence HCPs' attitudes

Include HCPs' views or perceptions about their own knowledge and competency to work with people with ID and MH problems	Explore other kinds of attitudes, such as attitudes towards sexuality or parenting issues in people with ID
English language quantitative studies	Describe services that provide care to people below 21 years of age
Published between 2006 – June 2020	Exclude review articles, commentaries, book chapters or case studies

Search Strategies

Table 2.2 lists the search terms chosen based on reading relevant literature and were combined to obtain the results of the literature search.

Table 2.2: List of search terms for literature review

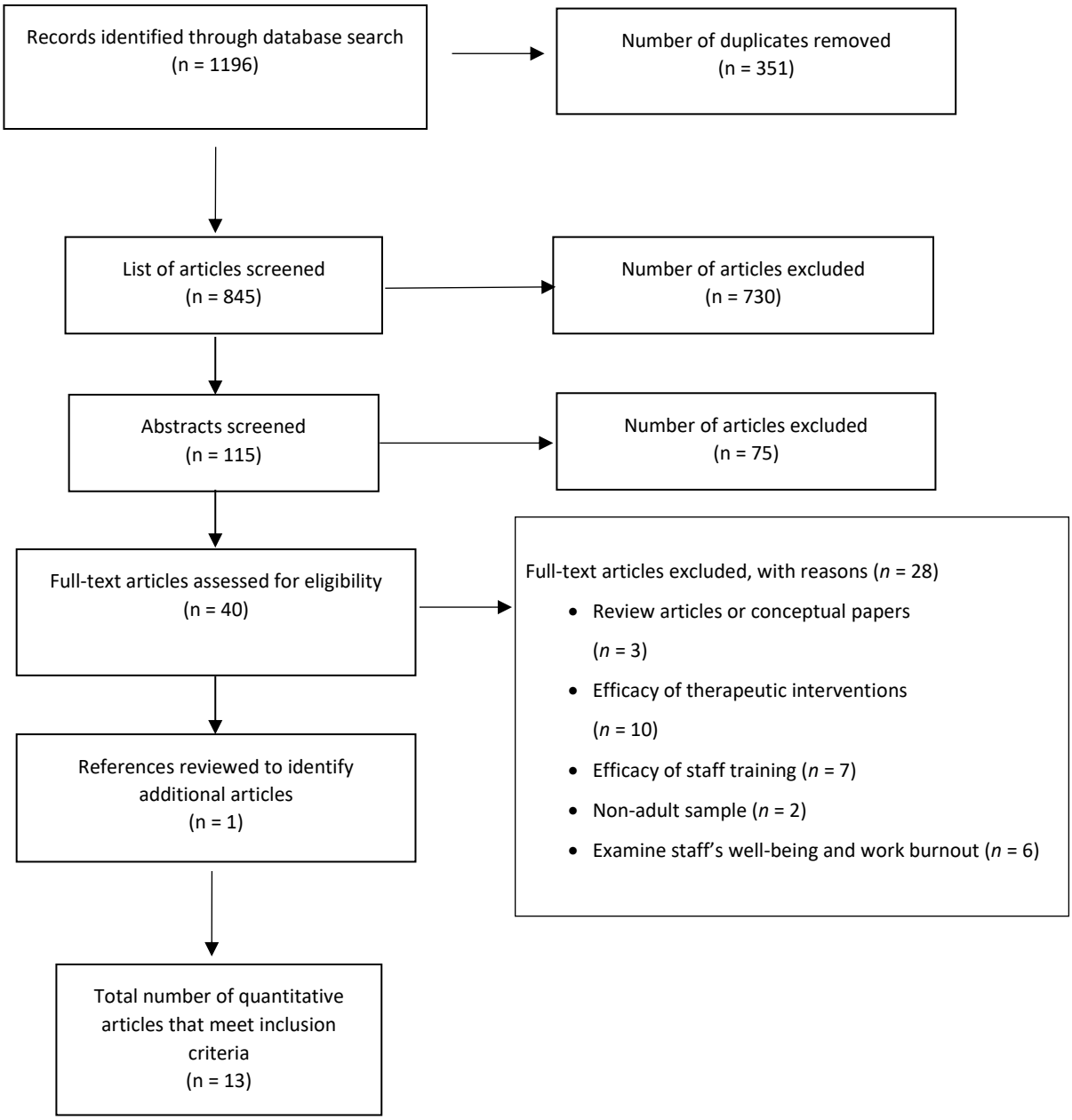
Attitudes	**Intellectual Disability**	**Mental Health**	**Professionals**
Attitu*	Intellectual disabili*	Mental health illness*	Staff
OR	OR	OR	OR
Beliefs	Learning disabili*	Psychiatr*	Therapis*
OR	OR	OR	OR
Perception	Mental retardation	Challenging behav*	Nurs*
OR		OR	OR
Experience		Dual diagnos*	Psych*

A total of five literature searches were carried out up until June 2020 which obtained a total of 1196 publications. These search terms were entered in the electronic databases PubMed,

OVID PsychINFO, ProQuest, CINAHL, MEDLINE, PsyARTICLES and ScienceDirect to identify peer-reviewed quantitative studies from 2006 to 2020. For publications that included a mix of different professionals, such as HCPs and support care staff, they were only included if the majority of the participants were HCPs. These publications were screened which removed 351 duplicates leaving a total of 845 publications. Subsequently, a further 730 publications were removed after reading the titles as they did not meet the inclusion criteria leaving a total of 115 publications. The abstracts of the remaining publications were read and 75 articles were removed as they did not meet the inclusion criteria which left 40 publications. These 40 publications were further inspected by reading the main text and 28 publications were excluded as they failed to meet the inclusion criteria which left only 12 studies left for quality assessment.

The reference sections of each of these 12 publications were examined to identify any further studies that met the inclusion criteria. One study was deemed suitable for the review and was added, thus 13 studies were included in this review. Figure 2.1 presents of a flow chart of the selection process.

Figure 2.1: Flow diagram of the systematic literature review



Quality Assessment Tool

The final 13 studies that met the inclusion criteria were evaluated and critically appraised to determine their quality and rigour. A quality assessment tool developed by Sale and Brazil (2004) was chosen. The authors adapted the theoretical framework by Lincoln and Guba (1986) to provide a deeper understanding and description of the quality (for example

trustworthiness, credibility and rigour) of quantitative research studies. The tool consists of seven main domains: Extraneous Variable, Ethical Issue, Rationale, Design, Research Sample, Missing Data and Statistical Analysis. These domains are further divided into 21 criteria that focus on evaluating the internal and external validity of the quantitative studies to determine their quality. The selected studies were assessed according to these criteria and a tick was provided when the studies achieved a criterion and a cross denoted that they failed to meet the criterion. The sum of the ticks was totalled up to provide a final score with a maximum score of 21 to be awarded.

For the purpose of the review, Bronze is awarded for studies with a score of 1 to 7 which denotes weak quality; Silver is awarded for studies with a score of 8 to 14 to denote moderate quality and Gold is awarded for studies with a score of 15 to 21 to indicate high quality.

Data Extraction

Relevant information from each study was extracted and recorded using a data extraction table. This table has 8 sub-headings to record relevant information such as aims, participant sample, methodology and results. The strengths and limitations of the 13 studies are also listed in the table.

Results

The results are presented in four sections: 1) Descriptive overview of the studies; 2) Quality Assessment; 3) HCP's attitudes and perceptions and 4) Impact of attitudes and perceptions on service delivery.

Descriptive Overview of the studies

This section provides a detailed description of the studies. The studies included in this review will be referred by the numbers allocated in the Table 2.3.

Countries

Four studies were conducted in Israel (Studies 1, 10, 11 and 12). Three studies were conducted in the UK (Studies 3, 4 and 6). Three studies were conducted in Australia (Studies 2, 9 and 13). One study was conducted in the USA and Singapore respectively (Studies 7 and 8). Study 5 was cross-cultural and conducted in the UK and Australia.

Table 2.3: Summary of quantitative studies included in the review

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
1	Araten-Bergman and Werner (2017) Israel	To examine how social workers view people with ID and psychiatric illness	279 social workers (219 females and 60 males with average age of 34.5 and worked for an average of 9 years)	Participants read a vignette, answered an adapted version of the Attribution Questionnaire 27 (AQ-27) and some items extracted from the Knowledge of Causes subscale of the Attitudes Toward Intellectual Disability Questionnaire (ATTID)	Factor analysis, analysis of variance (ANOVA), regression analysis	Stereotype of dangerousness was found to be the strongest predictor of discriminatory behaviours. Social workers were found to have higher levels of helping behaviour when they were less angry and pitied people with ID and MH problems	Detailed background literature with use of theoretical framework Clear hypotheses Identification analysis of extraneous variables	Lacks details of inclusion criteria of participants Convenience sampling
2	Edwards, Lennox and White (2007) Australia	To examine attitudes of Australian psychiatrists and perceptions of the MH problems of adults with ID	175 psychiatrists (96 males and 73 females, the rest did not indicate their gender)	Participants responded to a 28-item self-administered questionnaire that probed perceptions of psychiatrists across their spectrum of responsibilities	Descriptive statistics	Majority of psychiatrists expressed the MH needs of people with ID were not met. 75% of participants reported the overuse of psychotropic medication to treat aggression. 34% were less willing to provide MH service to people with ID. Overall, psychiatrists agreed that specialist mental health services are needed with specialist training in MH to work with the ID population	Includes details of questionnaire Include details about non-respondents	Only descriptive statistics used Low response rate Lacks discussion of ethical issues Lack validated measures

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
3	McCorkindale, Flemming and Martin (2017) United Kingdom	To identify how specialist ID staff perceives the MH problems of people with ID	210 participants comprised of nurses, support workers and managers (average age of 46, 71 males and 138 females) 109 qualified nursing staff (66% females and 34% males with average age of 46 years)	Participants completed the modified version of the Illness Perception Questionnaire – Schizophrenia Carers Version	Spearmen-Brown coefficient and Pearson's correlation analysis	Positive correlation was found between the MH problems of people with ID and the impact on HCPs' Staff perceive the MH problems will negatively impact the lives of people with ID Negative correlation between the treatment duration and positive outcomes Pessimistic view of outcomes for schizophrenia in people with ID.	Details of inclusion criteria of participants Includes details on adaption of questionnaire Relevant literature	Inconsistent psychometric properties of the questionnaire Nonprobability limited sampling in one geographical location
4	Mesa and Tsakanikos (2014) United Kingdom	To compare the differences in attitudes and self-efficacy towards people with ID and those with MH problems among mainstream HCPs	68 acute inpatient psychiatric staff. No other information is provided	Participants were randomised into two groups. One group completed a Community Living Attitudes Scale (CLAS) that included self-efficacy, and attitude questions pertaining to people with ID while the other group completed the same questionnaire with questions pertaining	Chi-square, *t*-test, Mann-Whitney U-test	Hospital staff did not have more negative attitudes to people with ID than people with MH. However, they were not willing to empower or encourage people with ID to self-advocate. They were not aware of service policies for people with ID. reported lack adequate training and experience to provide care to people with ID, hence were less confidence to assess and	Uses validated questionnaire to measure outcomes Appropriate statistical analysis chosen Use of randomization	Low response rate and sample size Did not include sample characteristics Lack details on ethical issues and consideration

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
				to people with mental health problems		treat them.		
5	Jess et al. (2008) United Kingdom, Australia	To examine the differences between the UK and Australian psychiatrists' knowledge and competency, and the impact of service quality and the need for specialist services for people with ID	294 UK psychiatrists and 205 Australian psychiatrists. No other information is provided.	Participants were asked complete the questionnaire that included a section on details of work experience with people with ID, views regarding the role of psychiatrist for people with ID and their views of knowledge, training experiences and quality of services	Chi-square, Mann-Whitney U-test	Both the UK and Australia psychiatrists reported having more positive views about their specialist ID services with a higher percentage in the UK sample. The UK sample had better training, higher levels of knowledge and reported more confidence to work with people with ID than the Australian psychiatrists.	Clear objectives of the research study Comparison between professionals in different countries Adequate background information about the differences in the service delivery between the countries	Lacks information about the sample characteristics (e.g years of working experience, gender, age) Different response rates between the two groups with one group that may affect validity of the results Lacked validated measures to explore attitudes and perception
6	Rose, Kent and Rose (2012) United Kingdom	To compare the attitudes and emotional experiences of specialist and mainstream HCPs	42 mainstream service participants (10 men and 32 women with average age of 43 years 8 months and worked for an average of 15	Participants responded to the Ten Minute Survey that contains an attitude scale and a measure of emotional experience They were also asked to rate their emotions working with different client types,	Non-parametric Mann-Whitney U-test, *t*-test, MANOVA, Pearson's coefficient	Specialist staff had more positive attitudes and more contact with people with ID No significant differences in attitudes between mainstream and specialist staff Specialist staff had higher positive emotions when working with people with ID	Clear aims and hypotheses High response rate Appropriate use of analysis	Additional extraneous variables such as gender, years of experience are not identified and explored Small representation of professionals with different specialities

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
			years in their chosen occupation), 21 of them were HCPs 42 specialist service participants (14 men and 28 women with average age of 41 years 5 months and worked for an average of 16 years in their chosen occupation), 24 of them were HCPs	those with ID and those with MH problems		than Mainstream staff Mainstream staff had higher positive emotions when working with people with MH problems	Identification of extraneous variable and taken into account during analysis Comparison between mainstream and specialist staff	
7	Ruedrich, Schwartz, Dunn & Nordgren (2008) United States	To compare the attitudes between psychiatry residents and those who have graduated regarding community living for	21 psychiatric resident graduates and 16 current residents	Participants completed Community Living Attitudes Scale, Mental Retardation version	t-tests, ANOVAs	No differences in the group mean scores between the two groups. Differences were found within the subscales of Empowerment, Sheltering and Exclusion Current residents were more likely to prefer people with ID to be sheltered and	Use of standardised instrument Provide information about non-respondent	Lacks clear aims Lacks description of analysis used Small sample size Respondents biases as the length of training

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
		people with ID				excluded while psychiatric graduates were more likely to more likely to favour empowerment in people with ID		provided is minimal and participants' characteristics ma explain the results
8	Sajith, Chiu, Wong and Chiam (2017) Singapore	To explore perceptions of care towards people with ID and MH problems among trainee psychiatrists and generalist doctors as well as understandin g their training needs and knowledge	28 non-specialist doctors and 20 trainee psychiatrists (26 males and 22 females with an age range from 25 to 36 years)	Participants completed the questionnaire that assessed knowledge and perception of psychiatric care for people with ID, clinical experience and training in ID and mental health problems	Chi square	Nearly 90% of respondents agreed that specialist team should manage people with ID, an overuse of medication and restraints to manage behaviours. Most agreed that postgraduate training was required and current training was inadequate. Majority agreed that people with ID were vulnerable to exploitation when accessing general MH services. Majority were willing to see people with ID and agreed that people with ID should have the same level of care as general population	Adequate response rate Clear aims Detailed literature background	Lacks consideration of extraneous variables Lacks generalisability Lacked validated measures to explore attitudes and perception Unclear on the internal consistency of the questionnaire
9	Torr et al. (2008) Australia	To compare the perceptions of psychiatrists over a decade from 1994 to 2004	170 psychiatrists (69% were male)	Participants completed 50-item questionnaire and open-ended questions on their opinions of assessment and management, and role of psychiatry in	*t*-test	Participants agreed people with ID were vulnerable to exploitation staying in acute wards. They indicated that they were better trained to assess and treat MH problems of people with ID compared to ten years ago.	Clear objectives in focusing the trend of attitudes over a 10- year period	Low response rate Lacks generalisability Lacks appropriate statistical analysis to note significant trends

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
				ID. The results of this questionnaire were compared to the previous results in 1994		Participants were supportive of additional training to become specialised in ID, dissatisfaction with mainstream MH model		
10	Werner and Araten-Bergman (2017) Israel	To examine differences in attitudes by social workers towards people with ID, MH problems and those with ID and MH problems	279 social workers (219 females and 60 males with average age of 34.5 and worked for an average of 9 years) – Same sample as in study 1	Participants read a vignette that is similar in study 1, answered an adapted version of the Attribution Questionnaire 27 (AQ27)	ANOVA, *t*-test, Pearson's coefficient	Majority of the participants reported pity, fear and anger as negative emotional responses. People with MH problems and people with ID and MH problems were perceived more dangerous than people with ID. Social workers reported less fear towards people with ID than the other two groups. They agreed on using more coercive and segregating behaviours toward individuals with MH problems and those with ID and MH problems DD. Social workers preferred segregation, coercion and avoidance when they perceived danger. felt fear and anger	Clear aims Findings are presented in a clear manner Clear focus on exploring attitudes and perceptions of healthcare professionals	Convenience sampling Lacks details of the participants' characteristics in the results The use of vignettes may not accurately capture the working experiences of healthcare professional working with someone with ID and mental health
11	Werner, Levav, Stawski and	To explore how psychiatrists	256 psychiatrists (53.6% males	Participants were asked to report any previous training and	ANOVA, regression analysis	Majority did not have adequate training to assess and treat MH problems of	Clear description of methodology Detailed	Response biases Non-random sampling

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
	Polakiewicz (2013a) Israel	evaluate their training, knowledge and skills working with people with ID and MH problems. To examine the availability of educational resources in their workplaces	and 46.4% females with average age of 47.9 and worked average of 14.1 years)	experience working with people with dual diagnosis, after which they were given two clinical vignettes and asked to provide likely causes for the patient's problems		people with ID, agreed the need to improve training due to poor knowledge and skills. Older male psychiatrists were previous training and exposure had higher levels of knowledge similar to those working in specialist service. Low available of educational resources on the topic related to people with ID include journal clubs and research	information about sample characteristics	Lacks the use of validated questionnaire

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
12	Werner, Stawski, Polakiewicz and Levav (2013b) Israel	To examine the opinions about their training, their knowledge in the MH needs of people with ID, skills and attitudes among psychiatrists with differing levels of experience	256 psychiatrists (53.6% males and 46.4% females with average age of 47.9 and worked average of 14.1 years) – Same sample as in Study 11	Participants filled in a questionnaire that asked them to rate their subjective knowledge and attitudes. They were also asked to read two vignettes, which are similar in study 11, and answer questions that assessed their objective knowledge	Chi-square	Most lacked knowledge to identify the MH needs in people with ID, perceive a lack of adequate training. Majority agreed that people with ID and MH problems have poor standard of treatment, need to have specialist services Majority expressed that people with ID can benefit from medication and counselling but not willing to treat them	Clear and detailed findings Details of recruitment strategy Relevant literature to support the study	Non-random sampling Low response rate Response biases, such as the possibility of social desirability Lack clear hypotheses and aims

No	Author (Year) and Country	Aims	Participants	Method of data collection	Method of Data Analysis	Key Findings	Strengths	Limitations
13	Weise and Trollor (2017) Australia	To investigate the attitudes, confidence and training needs for mainstream HCPs	566 mainstream HCPs comprised of different professional background (164 males and 401 females). 290 of them had more than 10 years of training.	Participants were asked to complete an online questionnaire. The questionnaire consisted of demographics and workplace details; attitudes towards providing services to people with ID; their level of confidence working with this population and their training and/or professional development needs	Descriptive analysis	Almost all the HCPs had professional contact with people with ID and MH problems and agreed that they should have equal access to mainstream services. However, they perceived that the MH needs of people with ID were not adequately met in the service. More than half of the professionals rated less confidence to detect MH problems and understand the effects of psychotropic medication on people with ID and MH problems Majority of them reported receiving training but found it insufficient when working with people with ID and MH problems	Use of measures with strong internal consistency Responses from a diverse range of HCPs Summary of key findings included in a table	Use of descriptive statistics Low response rate Results may be positively skewed Lack clear hypotheses

Participants and settings

Five studies (Studies 2, 5, 9, 11 and 12) reported on samples comprised of psychiatrists (n = 1100). Two studies (Studies 7 and 8) comprised of trainee psychiatrists and generalist doctors (n=85). Studies 1 and 10 consisted of medical social workers (n=279) and study 3 comprised mostly of nurses (n=109). Study 4 consisted of inpatient psychiatric staff (n=68) but did not provide the details of the participants' professional background. Study 6 comprised a mixture of HCPs working in different specialities, the majority of them were nurses (n=25), followed by psychologists (n=12), psychiatrists (n=5), occupational therapists (n=3) and one speech therapist. Some of the participants in studies 3 and 6 were unqualified staff (such as support workers, nursing assistants and managers) which formed a minority in this review. The majority of the studies comprised of HCPs working in mainstream setting. Only four studies (Studies 3, 6, 11 and 12) included HCPs working in specialist settings including hospitals and social service sectors (n=171). Study 13 comprised a mixture of HCPs working in mainstream services, the majority of them were nurses (n=303), followed by occupational therapists (n=49), psychiatrists (n=41), psychologists (n=81) and social workers (n=60).

Studies 2, 5, 9, 11 and 12 were carried out through their respective professional associations or councils which posted the questionnaires to potential participants. Studies 4, 7 and 8 were conducted at a hospital site whilst studies 1 and 10 were conducted in community-based social and mental health services. Studies 3, 6 and 13 were carried out at various recruitment sites including hospital and community sites.

Studies 1 and 10 used the same sample of social workers for both studies. These studies were included as separate studies because they had different research hypotheses and aims.

Study 1 investigated social workers' attributions of challenging behaviours in people with ID and MH problem whilst Study 10 investigated the differences in how social workers viewed people with ID (with no MH problems), people with MH problems (with no ID) and people with ID and MH problems.

Studies 11 and 12 similarly used the same sample of psychiatrists for both studies. These studies were included as separate studies because study 11 compared the differences between subjective and objective knowledge among psychiatrists and investigated their views regarding their ability to care for people with ID whilst study 12 examined psychiatrists' perceived level of knowledge related to ID, attitudes to people with ID and MH problems and their willingness to work with this client population. In addition, study 11 examined the level of resources and support that psychiatrists receive in their places of work.

Research design

All the studies used cross-sectional designs to investigate their research aims and hypotheses. Three studies compared participants' responses related to different client population groups. Study 10 compared social workers' attitudes towards people with ID (no MH problems), people with MH problems (no ID) and people with ID and MH problems. Study 4 used a randomised between-subject design to investigate the differences in participants' attitudes towards two different client groups: people with ID and MH problems and people with MH problems (no ID). This was similarly adopted in study 6, but the participants were not randomised and instead grouped according to their service specialty.

Four studies compared the responses between different groups of HCPs. Study 5 compared the knowledge, attitudes and willingness to work with people with ID between psychiatrists

in the UK and Australia. Study 6 compared the attitudes and emotional reactions between mainstream and specialist HCPs. Study 8 compared the attitudes regarding community living between psychiatry graduate residents and those general medical staff receiving psychiatric training. Study 9 compared 2004 data with the previous findings conducted in 1994 to investigate differences in attitudes and knowledge among the psychiatrists over ten years.

Four studies (Studies 2, 8, 11 and 12) examined the participants' level of knowledge related to ID, their attitudes towards people with ID and MH problems and their views on whether MH needs of people with ID were adequately met in mainstream services. Study 1 focused on how social workers attribute the challenging behaviours in people with ID and how they would react to those behaviours. Study 3 investigated specialist ID staff's perceptions towards the MH problems (i.e schizophrenia) in people with ID such as the impact of MH problems on their lives and their likelihood of recovery. Study 13 examined the confidence among HCPs in their ability to provide services to people with ID and their views about whether people with ID should have access to mainstream services.

Measures

All the research studies used self-report measures together with a variety of procedures and questionnaires to measure the attitudes and perceptions of people with ID and MH problems. Studies 11 and 12 used case vignettes to assess for objective knowledge in participants whereas the participants in Studies 1 and 10 read two case vignettes before completing the Attribution Question-27 (AQ-27; (Corrigan et al., 2003) which indicated internal consistency for subscales ranging from 0.7 to 0.89. Study 1 used Knowledge of Causes subscale of the ATTID (Morin et al., 2013) together with AQ-27. The researchers did

not provide information on its internal consistency but findings from Morin et al. (2013) indicate a moderate internal consistency of 0.59 for this subscale.

Studies 4 and 7 used the Community Living Attitudes Scale (CLAS; (Henry et al., 1996) to measure participants' attitudes towards empowering and integrating people with ID and mental health problems in the community. There was no information about its internal consistency in the studies but Henry et al. (1996) reported stable internal consistency of above 0.7 and good construct validity. Study 4 additionally used a self-designed questionnaire to measure participants' views of self-efficacy towards people with ID. No further information of the self-designed questionnaire was provided other than high internal consistency of 0.94.

Study 3 used a modified version of the Illness Perception Questionnaire – Schizophrenia Carers Version (IPQ-SCV; (Barrowclough et al., 2001). The questionnaire underwent a few iterations and the final version achieved an internal consistency ranging from 0.496 to 0.862.

Study 6 used a self-designed questionnaire called the "Ten Minute Survey" which adapted the attitude scale developed by Hardy (2006) and included the Emotion scale developed by Gill et al. (2002). Internal consistency of this new survey demonstrated good internal consistency of 0.824. Study 13 used the questionnaire from study 6 and an unpublished questionnaire that was previously piloted. No information about the questionnaire was provided other than high internal consistency of 0.92.

Five studies (Studies 2, 5, 8, 9 and 12) used a modified version of questionnaire from previous research (Lennox & Chaplin, 1995, 1996). The authors in Studies 2, 5 8 and 9 did not provide information regarding the changes made to the questionnaire and its internal consistency. The authors in study 12 designed a new questionnaire including 14 items on

the role of psychiatry in ID from Lennox and Chaplin (1995), four items from the Psychiatric Disability Attribution Questionnaire (Corrigan et al., 2001) that measures the attitudes towards people with ID and MH problems and six new items to measure specific attitudes relevant to psychiatrists. The questionnaire indicated a good internal consistency of 0.73.

Analysis

All the studies, except study 2 and 13, used inferential statistics to analyse the results. The common statistical tools were ANOVA, chi-square and t-test. Study 2 and 13 only used descriptive statistics.

In summary, some studies chose to use standardised measures found in the literature while others developed new questionnaires to address the aims of their research questions. Overall, majority of the studies (which reported on this) indicated good internal consistency with the exception of study 3 that showed inconsistent psychometric properties of the questionnaire used.

Quality Assessment

Two of the studies (Studies 1 and 6) attained Gold which indicates a high standard quality. These two studies stood out for taking into account the extraneous variables and controlled for them during analysis. In addition, they provided clear description of hypotheses and described the data procedures clearly. The authors of these studies defined the outcome measures used to investigate the attitudes of HCPs and chose appropriate statistical tests.

Ten of the studies (Studies 3, 4, 5, 7, 8, 9, 10, 11, 12 and 13) attained Silver which indicates a moderate standard quality. There were some weaknesses in these studies, such as not including clear descriptions of hypotheses, lacked clear objectives, failed to describe

outcome measures and lacked clarity of the research purpose. They did not identify and take into account some extraneous variables such as age, gender amount of contact and training. Overall, these studies provided sound descriptions of the methodology and data procedures, and the statistical tools used for analysis.

Study 2 attained Bronze which indicates a poor standard quality. The study failed to describe ethical issues, lacked clear hypotheses and did not state the research purpose. There was no clear description of the statistical procedures used.

None of the studies mentioned the use of power calculations to determine the sample size. In addition, there were no confidence intervals provided for the main results and there were no explanations provided to address non-respondents or missing data. Table 2.4 shows the ratings for each study.

Table 2.4: Quality assessment of quantitative studies

STUDY NO			1	2	3	4	5	6	7	8	9	10	11	12	13
Area of critical appraisal	**Criteria**		**Araten-Bergman and Werner (2017)**	**Edwards, Lennox and White (2007)**	**McCorkindale, Flemming and Martin (2017)**	**Mesa and Tsakanikos (2014)**	**Jess et al. (2008)**	**Rose, Kent and Rose (2012)**	**Ruedrich, Schwartz, Dunn & Nordgren (2008)**	**Sajith, Chiu, Wong and Chiam (2017)**	**Torr et al. (2008)**	**Werner and Araten-Bergman (2017)**	**Werner, Levav, Stawski and Polakiewicz (2013a)**	**Werner, Stawski, Polakiewicz and Levav (2013b)**	**Weise and Troller (2017)**
Truth value (Internal validity)	Extraneous variable	Identification of extraneous variables	✓	×	×	×	×	✓	×	×	×	×	×	×	×
		Extraneous variables controlled for in analysis	✓	×	×	×	×	✓	×	×	×	×	×	×	×
	Ethical issues	Informed consent stated	✓	×	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Ethical review undertaken	✓	×	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓
Applicability (External validity / Generalizability)	Rationale	Statement of the research purpose	✓	×	✓	×	✓	✓	×	×	×	✓	✓	✓	✓
		Objective or aims explicitly described	✓	×	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	✓
		Outcome measure(s) defined or described	✓	×	✓	✓	×	✓	✓	×	×	✓	✓	✓	×
	Design	Description of the setting under which data collected	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Design stated explicitly	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Research sample	Description of sampling selection	✓	✓	✓	×	✓	✓	×	✓	✓	✓	✓	✓	✓

		Inclusion and exclusion criteria of participants defined	✗	✗	✓	✗	✗	✓	✗	✗	✗	✗	✗	✗	✗
		Study population defined	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Source of participants stated	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Missing data	Statement about non-respondents	✗	✓	✗	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗
		Missing data addressed	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
		Power calculation to assess adequacy of sample size	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
	Statistical analysis	Statistical procedures described	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		p values stated	✓	✗	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✗
		Confidence intervals given for main results	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
		Data collecting procedures described	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		At least one hypothesis stated	✓	✗	✗	✓	✓	✓	✗	✗	✓	✓	✗	✗	✗
		TOTAL	16	7	14	10	13	17	11	10	12	14	13	13	11
		RATING	**GOLD**	**BRONZE**	**SILVER**	**SILVER**	**SILVER**	**GOLD**	**SILVER**	**SILVER**	**SILVER**	**SILVER**	**SILVER**	**SILVER**	**SILVER**

Healthcare professionals' attitudes and perceptions

This section discusses the findings of the studies in greater detail. The findings of the 12 studies can be summarised into three sub sections which are 1) Training, knowledge and competency, 2) Vulnerability, segregation and empowerment and 3) Emotional reactions

Training, knowledge and competency

MHCPs in the research studies perceived a lack of adequate training in and knowledge of the MH needs of people with ID. Australian psychiatrists in study 2 reported a lack of adequate training also found in study 5, which indicated that Australian psychiatrists received less training, had a lower level of knowledge and poorer confidence to meet the MH needs of people with ID as compared to UK psychiatrists. Additionally, the Australian psychiatrists in studies 2 and 5 reported a reluctance to work with this client population. Study 9 which found an improvement among the Australian psychiatrists between 1994 and 2004 whereby they viewed themselves better trained to assess and treat the MH problems of people with ID when compared with the sample ten years ago.

Inpatient staff in study 4 reported low levels of self-efficacy with regards to working with people with ID and MH problems. They reported that they did not receive adequate training and experience to work with this group, and as such felt less confident to provide treatment and communicate with this client population. Because of their lack of training and experience, they perceived that they were inadequately equipped to support people with ID, to make decisions about their care and help them express their views regarding their treatment and care plans. This was similarly reported in study 13 in which the majority of HCPs reported they received inadequate professional training, lacked the knowledge, skills and training to manage the MH problems of people with ID after they graduated from their

undergraduate course. Trainee psychiatrists and newly graduated doctors in study 8 perceived that the current training model was inadequate for them to gain sufficient knowledge and skills to work with people with ID. The findings in study 11 found that psychiatrists who were older, spent more time working with people with ID and had previous training in the field of ID and MH, perceived themselves as having more knowledge and skills. The actual level of knowledge among psychiatrists was assessed to be low in this study and the psychiatrists reported a lack of educational resources in their place of work, hence found it difficult to improve their knowledge and skills. The psychiatrists in study 12 preferred not to treat people with ID due to their lack of training and poor knowledge.

The participants (i.e psychiatrists, psychiatric residents and newly graduated doctors) in these studies (Studies 2, 5, 8, 9, 11 and 12) agreed on the need for further training before they could be more confident to address the MH needs in people with ID. Psychiatrists in studies 2 and 9 indicated that training in the field of ID should be offered to all mainstream medical staff. The authors of studies 8, 9 and 12 emphasised the need for training in ID for mainstream MH staff because they were likely to come into contact with people with ID when they accessed mainstream services. However, half of the trainee psychiatrists in study 8 reported that specialist ID training should be limited to HCPs working in specialist ID settings. Participants in all these studies provided suggestions for delivering postgraduate training on the MH needs including assessment and treatment of people with ID and having educational resources dedicated to this field, attending seminars or journal clubs, and conducting research projects. The participants were generally positive towards attending such training to improve their competency and knowledge in this field.

Vulnerability, segregation and empowerment

The medical staff in studies 8 and 9 suggested that people with ID and MH problems need to be segregated when accessing mainstream MH services as they perceived this group as vulnerable and easily exploited by other patients in acute general wards.

Study 6 found that specialist staff had more contact with people with ID and more positive attitudes than mainstream staff. However, no significant difference in attitudes between these two groups was found after taking into account the presence of extraneous variables such as training and professional contact. Similarly, study 4 did not find any differences in attitudes to people with ID and MH problems and those with MH problems among inpatient psychiatric staff.

Social workers in study 10 were found to have stigmatising attitudes towards people with ID and MH problems as well as people with MH problems (no ID). The findings indicated that social workers viewed these two groups of client population as more dangerous and thus requiring segregation in comparison to people with ID (no MH problems). There were no differences in perception of dangerousness between people with ID and MH problems and those with MH problems (no ID). Additionally, they viewed that people with ID and MH problems lacked control over their challenging behaviours. These findings were explained by the authors in (their other) study 1 in which they indicated that social workers were more likely to attribute challenging behaviours of people with ID to biological and internal causes (such as chemical imbalance of the brain, lack of willpower and bad character), hence they did not consider people with ID and MH problems to be responsible for their challenging behaviours.

Social workers in study 1 were more likely to recommend segregation for people with ID and MH problems when they attributed their challenging behaviours to biological and internal causes. The specialist staff in study 3 perceived people with ID as less likely to recover from their MH problems despite receiving treatment and predicted that the MH problems of people with ID would significantly impact negatively the lives and well-being of their carers. Inpatient staff in study 4 were less willing to empower people with ID and MH problems as compared to those with MH problems (no ID). Findings of study 7 indicated differences in attitudes concerning empowerment and sheltering among medical staff with and without additional training whereby those with postgraduate training (i.e. exposure and knowledge in the field of ID) were more supportive of empowering people with ID to make decisions regarding their treatment and life choices such as getting married than staff without such training. Medical staff without additional postgraduate ID training had the view that people with ID should live in sheltered facilities as they are unable to deal with challenges faced in the community.

Emotional reactions

Study 6 found that HCPs providing mainstream services (i.e. psychiatrists, nurses, psychologists and occupational therapists) reported more negative emotions towards people with ID and MH problems than those providing specialist ID services. The authors of the study argued that increased interactions and contact with people with ID and MH problems contributed to more positive emotions among specialist staff than mainstream staff.

The findings in studies 1 and 10 indicated that social workers reported a mixture of pity, fear and anger towards people with ID and MH problems. Social workers in study 10 who

perceived people with ID and MH as dangerous were more likely to express fear and avoid interacting with them. However, the findings in study 1 indicated that fear and anger did not predict an inclination to discriminatory behaviours or coercion. Social workers were also more likely to express pity when they attributed the challenging behaviours of people with ID to biological causes and were more inclined to help them.

Impact of attitudes and perceptions on service delivery

This section describes how MH services are influenced by HCPs' attitudes and perceptions towards people with ID and MH problems. The studies can be divided into the following two areas:

Use of medication and restraints

An over-reliance on the use of anti-psychotic medication in mainstream MH services among psychiatrists had been noted (Studies 2, 5 and 12), which the authors suggested was due to the MH needs of people with ID being attributed to biological causes without considering social or environmental factors. Trainee psychiatrists and non-specialist medical staff in study 8 similarly reported an overuse of medication and restraints employed to manage challenging behaviours of people with ID in hospital settings. HCPs lacked confidence to work with this group because of the lack of knowledge regarding the potential adverse effects of psychotropic medication. Social workers in study 1 agreed that people with ID and MH problems needed to comply with medical treatment and that they lacked competency in making medical decisions. Hence, social workers preferred to act on behalf of people with ID when it came to medical treatment and saw little need to involve and discuss treatment with them, perceiving that it was in their best interests to comply with medical treatment to manage their challenging behaviours.

Development of specialist MH ID services

The psychiatrists in five studies reported that mainstream services were inadequate and ill-equipped to meet the MH needs of people with ID due to inadequate knowledge and low competence to provide psychiatric care (Studies 2, 5, 8, 9 and 12). The authors of the studies recommended the development of specialist MH ID services that offered separate psychiatric services to people with ID and MH problems tailored to their unique MH needs. Psychiatrists in studies 9 and 12 suggested specialist MH ID services within mainstream MH settings. The participants in study 13 felt that people with ID should have same access to mainstream services as the general population but perceived that they would receive poor quality service because their MH needs would not be adequately met given the limited resources.

Additionally, the participants considered more training opportunities would be available in the specialist MH ID services and that increased exposure to people with ID would improve HCPs' attitudes towards them. Indeed, study 11 found that psychiatrists working in specialist services had more access to educational resources dedicated to the knowledge of MH problems of people with ID as compared to those working in mainstream services. The authors in study 6 argued that factors such as the nature of contact and organisational work culture, could have an impact on the formation of positive attitudes and service delivery. HCPs in study 13 prioritised high importance to attend further training, for example face to face training seminars and workshops and believed that their management would be supportive towards their professional development in this area.

Discussion

This paper examined the attitudes and perceptions of HCPs working with people with ID and MH problems well as the impact of these attitudes and perceptions on the delivery of MH services to this client population. In all the thirteen papers that were included, this review rated two papers to be of good quality (Gold standard), ten papers to be of acceptable quality (Silver standard) and one paper to be of poor quality (Bronze standard). The one poor quality paper (study 6) had issues with the research design and did not provide a clear rationale. Nonetheless, the paper had its merits and the findings were consistent with the other papers. Most of the papers encountered issues with internal validity, such as not identifying and controlling for extraneous variables (e.g. gender, age, level of experience or work environment). This suggest that the findings of the review need to be interpreted with caution and no casual references can be drawn to explain the HCPS' attitudes and perceptions towards people with ID and MH problems. Despite this, the findings across the papers show consistency and are in line with other review findings (Pelleboer-Gunnink et al., 2017; Werner & Stawski, 2012).

Most of the findings identified that MHCPs had limited knowledge in the field of ID and a lack of training to understand the MH needs of people with ID. In addition, they noted a lack of available resources in mainstream work settings for HCPs to improve their knowledge and skills. They expressed feeling of pity, fear and anger towards people with ID and MH problems, often viewing them as dangerous and unable to control their behaviours. Negative attitudes and perceptions towards this client population influenced MHCPs' willingness to treat them in mainstream MH service and many advocated specialist MH ID services to provide care and management. Reluctance to offer mainstream healthcare

services to people with ID suggests that people with ID and MH problems are less valued than the general population, resulting in further segregation as due to their MH problems they may be denied societal role participation in other aspects of their lives, such as employment and social relationships and interactions. The MHCP participants of these studies generally perceived more training and experience resulting in a more favourable attitudes towards this client group. However, although SHCPs (with more knowledge and experience) indicated more favourable attitudes and positive emotions when compared to MHCPs, they were nevertheless pessimistic regarding recovery outcomes for people with ID and believed that their MH problems would have a significant and negative impact on carers' wellbeing.

The findings of this review indicate that knowledge and competence of MHCPs need to be improved through exposure and contact with people with ID in addition to specialist ID training. Support from management is needed to provide educational resources and training opportunities, such as allowing MHCPs to attend professional courses dedicated to the field of ID and MH. Despite considerable improvements that have been made to integrate people with ID to access mainstream services for their health conditions, there remains a reluctance among HCPs to assess and treat MH problems of people with ID. Costello et al. (2007) found that additional training may improve attitudes towards people with ID and an increased awareness of their MH problems. The results in study 6 is an exception that found the amount of training and frequency of contact did not account for significant differences in attitudes between mainstream and specialist staff which could suggest that external factors such as the nature of contact is also important in the formation of positive attitude. However, the findings of that study found that the amount of training has a significant impact on the positive attitudes in both mainstream and specialist staff. Research has

shown that regular quality contact with individuals with ID can lead to more positive feelings and reduced levels of prejudice, and subsequently to more positive attitudes (Keith et al., 2015; Manetti et al., 2001; McManus et al., 2011; Piercy et al., 2002).

Although MHCPs express a preference for having specialist MH ID services to manage the MH problems of people with ID, there are some instances that people with ID will inevitably continue to access mainstream services for their MH problems. People with ID are found to disproportionally access emergency hospital services and are thus rarely seen by a psychiatrist with specialist ID training and knowledge to manage their MH crisis (Lunsky et al., 2011). HCPs in mainstream services are inclined to focus on the severity of the cognitive impairment rather than the severity of the MH symptoms, hence symptoms of people with mild ID or borderline level of cognitive functioning may be ignored or undetected, denying them the appropriate help that they require (Spassiani et al., 2017; Tint & Lunsky, 2015). Thus, poor screening and assessment by mainstream staff and late referral to specialist MH ID services pose an additional barrier for people with ID and MH problems to access appropriate services (Standen et al., 2017; Whittle et al., 2018).

Many HCPs in this review expressed the view that specialist MH ID services are more equipped to meet the MH needs in people with ID, some authors have argued that having such specialist services may not be feasible due to increased costs in providing such resources and limited opportunities for HCPs to receive training in working with this client group (Leyin, 2011; Scior & Grierson, 2004; Standen et al., 2017). The issue of training costs and opportunities to work with people with ID are not adequately addressed in the studies reviewed here. Whittle et al. (2018) carried out a review and found that there is no clear referral pathway for people with ID to access specialist MH ID service and they are not

identified as requiring MH services when transitioning from one service to another. Hence, utilisation remains low even though specialist ID MH service may provide a better quality service and more favourable outcomes. Bhaumik et al. (2008) found that only a small number of people with ID accessed specialist MH ID services due to poor collaboration with general service providers as they were not aware of these specialist services. As such, the costs of establishing a specialist MH ID service with additional training for staff may outweigh its benefits.

The current review suggests that MHCPs should receive additional ID training and MHCPs are supportive of this idea, however there could be a lack of support from the organisation's management for such training as they only serve a small minority of SUs. Moreover, MHCPs who often face high levels of stress and burnout with high work demands and responsibilities that affect their level of job satisfaction (Langdon et al., 2007; Yang et al., 2015) may not want to consider undergoing additional specialist ID training to work and treat the MH problems of people with ID in mainstream setting. Hence, organisational barriers need to be addressed in order for MHCPs to be inclined to attend such training.

MHCPs without additional ID training and work experience may continue to perpetuate negative attitudes, stereotypes and perceptions, which may have an impact on their career decisions and willingness to provide services to this population. Negative attitudes and perceptions held by HCPs may trickle down to unqualified support staff as the latter usually receive their training and knowledge from HCPs (Bates et al., 2004; Woodward & Halls, 2009). The theory of Social Role Valorization (SRV) describes how different groups of people are identified and assigned value on their roles in the society (Wolfensberger, 1983, 2000). For example, staff with negative attitudes and perceptions of people with ID and MH

problems may label this group as 'different', viewing them as less valued and denying them access to the common resources and opportunities to improve their quality of life, which in turn may reinforce the segregation of this particular population from society (Wolfensberger, 2002). By improving HCPs' attitudes and perceptions of people with ID and MH problems they may become more inclined to create positive valued social roles for this vulnerable population and hence increase their chances of integration.

Findings of the current review also indicate that specialise staff are pessimistic about recovery outcomes when working with people with ID and MH problems. A possible explanation is that the carers of people with ID are ill-equipped and unable to cope with complex care demands after their relative has been discharged. This suggests that specialist staff need to provide additional services for carers of people with ID and MH problems, such as providing them with training and resources to increase their knowledge and skills on how they can manage after discharge.

This review also found that a significant number of HCPs viewed people with ID and MH problems as being vulnerable to exploitation and thus considered segregation from other patients necessary. They were not inclined to involve them in decision-making related to their own MH condition and many viewed people with ID and MH problems as dangerous. However, whether this was due to the MH problems or the ID (or a combination of both) is not clear as the similar views towards people with MH problems (without ID) were recorded.

Many HCP participants included in this review saw no need to empower people with ID to understand more about their conditions and treatment from MH or general health services. Hall and Deb (2008) found that people with ID lacked knowledge of their medication and were not informed by HCPs why the medications were prescribed. This may reflect the

findings above, i.e. many HCPs view people with ID to lack competency to understand their MH conditions and as such, are unwilling to empower them or consult them during the treatment process.

Moreover, MHCPs included in this review acknowledged over-reliance on psychotropic medication and did not know how to address this issue. They appeared to lack knowledge of alternative non-pharmacological approaches such as identifying and understanding challenging behaviours using Functional Behaviour Analysis (FBA) and Positive Behavioural Support (PBS; Allen, 2009). Findings from a prevalence study revealed that 70.57% of people with ID were prescribed psychotropic medication when they accessed MH service (Bowring et al., 2017). An initiative in the UK called Stopping over-medication of people with learning disability, autism or both (STOMP) addresses the concerns regarding the use of psychotropic medication in people with ID and provides guidelines for medical professionals on appropriate use of psychotropic medication in people with ID (National Health Service England, 2016). There are also public campaigns to educate different stakeholders (including people with ID and their carers) on how they can work with medical professionals to ensure that the use of psychotropic medication remains minimal (Branford et al., 2019). There are also positive efforts made to reduce use of psychotropic medication in people with ID and MH problems using PBS (Conway et al., 2019; Gerrard et al., 2019).

Limitations

One of the major limitations of the current review is that the search was limited to quantitative studies and did not include qualitative studies that explore in-depth personal experiences of HCPs providing care towards people with ID and MH problems. This

limitation will be addressed in the next chapter which presents a meta-synthesis review of relevant qualitative studies.

The studies reviewed here are correlational research designs and thus are unable to establish casual relationships between factors hence is not possible to ascertain whether lack of knowledge and experience are causal factors that contribute to negative attitudes in HCPs. Similarly, the findings are unable to confirm that having additional training will lead to an improvement in the attitudes.

The reviewed research uses self-reported measures and participants may have a tendency to respond in what they consider to be a socially desirable manner (Paulhus, 1991). The studies selected in this review lack a standardised way of measuring attitudes and perceptions. Studies employed a variety of standardised questionnaires based on different theoretical models of attitudes, perceptions and attributions. For example, the contact theory is used to explain how attitudes can be improved with more frequent contact while the attribution theory is used to explain how lack of knowledge and understanding can contribute to negative attributions about the MH problems of people with ID. The use of researcher-developed and non-standardised questionnaires means that there is no standard way of measuring attitudes and makes it difficult to compare findings across different attitudinal studies.

The samples in this review predominantly consist of medical staff, mostly psychiatrists, and findings may not generalise to other healthcare professional groups such as nurses and allied health professionals. The differences in the perception and attitudes towards people with ID may be attributed to the sample of HCPs working in different work environments, such as hospital and community settings where there could be varying levels of

organisational support and this was not investigated in detail. Lastly, most studies employed relatively small sample sizes and were carried out mainly in Western countries where the cultures and clinical practices may be different from other parts of the world. The one Asian study included in this review may not be representative and further studies are needed to explore the attitudes of HCPs in Asian countries.

Clinical implications

There needs to be a clear referral pathway for people with ID to access specialist MH ID services to ensure that it will be adequately utilised. Besides addressing the MH problems of people with ID, the role of specialist MH ID service can be expanded to support MHCPs when they encounter people with ID accessing general health or MH services. Hence, training of MHCPs should provide them with information about the specialist MH ID services and the types of cases appropriate for referral. SHCPs can provide MHCPs with training on the alternative approaches to address the challenging behaviours in people with ID and provide consultations to ensure that people with ID only receive psychotropic medication as a last resort. Specialist MH ID services could be established in community settings to support mainstream MH services where SHCPs and MHCPs can collaborate with carers to provide training and resources to reduce inpatient hospital admission rates in people with ID. This would improve the accessibility and utilisation of specialist MH ID services as people with ID can more easily access them near to their homes.

Mainstream medical staff should have some exposure to working in specialist MH ID services to gain clinical experience of this client group. Having some experience working in a specialist MH ID setting would encourage them to consider whether they wish to specialise in this sub-speciality field and thus potentially improve recruitment in an under-staffed

clinical area. However, skills and experience in ID would still be useful even when they decide to specialise in other clinical specialties as people with ID access other health services, hence these clinicians would be better prepared and more confident to work with this client population.

Additional factors such as organisational work culture (Humphreys et al., 2020) can contribute to the development of positive or negative attitudes towards people with ID and MH problems among HCPs. HCPs should be encouraged to attend professional training to improve their knowledge and competency working with people with ID with the support of their organisations. Informal learning opportunities such as educational resources, supervisions and journal clubs or case discussion meetings should be available and accessible for HCPs to upgrade their skills and knowledge regularly.

Conclusions

This review highlights that HCPs may experience a mixture of attitudes and feelings whilst working with people with ID and MH problems, depending on the clinical context, level of training and work experience. MHCPs expressed the need for specialist MH services to target the specific MH needs of people with ID and offered possible suggestions on how to increase HCP' knowledge and expertise. Thus, recommendations are made to provide training for MHCPs who may encounter people with ID and MH problems. The availability of training opportunities may improve attitudes towards people with ID and increase confidence in providing MH services to this client population although more evidence is needed to establish this link.

The next chapter focuses on reviewing qualitative studies that explore the personal experiences of HCPs providing services and care to people with ID and MH problems. Another literature search was conducted and meta-synthesis was carried out to identify common themes reported in the selected qualitative studies.

Chapter 3: Exploring the experiences of healthcare professionals providing services to adults with intellectual disabilities and mental health problems – A qualitative review and meta synthesis

Introduction

Many governments have guidelines and legislature to promote people with ID to access mainstream services. For example, the UK government published a document entitled *Valuing People (*Department of Health, 2001) to encourage accessibility of mainstream services for people with ID.

There has been an increased interest in using qualitative methods in the field of ID to explore subjective experiences among different groups including people with ID themselves when accessing MH services and HCPs working with people with ID and parents/carers of people with ID (Beail & Williams, 2014; Ryan et al., 2014). For example, parents of people with ID have shared their views and experiences of interacting with HCPs (Doody et al., 2018), people with ID have related their experiences of services received (Ferguson et al., 2010) and of treatment (Lewis et al., 2016), and support staff have described their experiences of taking care of people with ID in a residential setting (Ćwirynkało et al., 2017).

However, there has as yet been little research on the experiences of HCPs providing services or taking care of people with ID and MH problems. Research involving HCPs has used quantitative methods to examine knowledge, skills or perceptions of people with ID without exploring personal experiences of working with this client group. A major issue in providing MH services is the impact on the stress levels of HCPs as a result of high work burden which may affect levels of work satisfaction (Edwards et al., 2003). HCPs have reported high levels

of stress working with people with ID in a variety of work settings (Søndenaa et al., 2015) and it is therefore important to understand the challenges that HCPs experience when working with people with ID and MH problems in order to gain an understanding of what causes this stress.

Key findings from the quantitative review

The findings from the quantitative review show that MHCPs lack adequate training in and knowledge of working with people with ID and their mental health needs. Most of the MHCPs agreed that they need further training and educational resources to gain more confidence to address the MH needs of this population. There is a common view among MHCPs that people with ID are vulnerable and dangerous and require to be segregated from the general population when seeking MH services. These negative perceptions are linked to their emotional reactions of pity, fear and anger which contribute to their lack of willingness to interact or work with this population.

The quantitative review also found that there is a strong reliance on the use of medication to address MH problems, without considering alternative treatment approaches. MHCPs do not have clear established protocols on the use of medication for people with ID. The establishment of specialist MH ID services to offer separate psychiatric services was favoured as were training opportunities for mainstream healthcare professionals in order to increase their exposure and improve their attitudes towards this population.

So far, there has been no qualitative review of HCPs' experiences and perspectives to understand their struggles and difficulties in working with this specific client population. The quantitative data did not provide much insight into how HCPs' experiences affect their

working practice or how HCPs identify their roles and the services they provide for people with ID.

Collating and synthesising qualitative findings are becoming increasing common and offer a rich source of easily accessible data that can be used for policy making. This approach was considered as it can complement the quantitative findings by providing greater breadth and depth, thus offering insight into the views and experiences of a variety of professionals. Taken together, both reviews have the potential to inform the development of guidelines and clinical practice for HCPs who work with this population.

Aim of the review

The purpose of this review is to combine and analyse data from qualitative studies that report on the experiences of HCPs providing services or care to people with ID and MH problems. This qualitative review complements the previous quantitative literature review presented in Chapter 2 by focusing on the dynamic relationship between HCPs and people with ID when they access MH services. The review will provide a quality assessment of the selected studies and a meta-synthesis to address the following aims:

1) to explore how HCPs experience their work of providing services and care to people with ID and MH problems

2) to explore the challenges that they encounter that affect their service delivery.

Gaining insight into the unique experiences of HCPs and their views may help to identify the level of support they require to improve their work and how they meet the MH needs of people with ID.

Method

Literature Search

The objective of the search was to identify peer-reviewed studies that explore the experiences of HCPs who provide services or care to people with ID and MH problems. Definitions of terms such as HCPs and MH problems are provided in the List of Terminology section (page xvi) of the research thesis. Table 3.1 shows the inclusion and exclusion criteria that were applied to the studies remaining after duplicates were removed.

Table 3.1: Inclusion and exclusion criteria for qualitative review

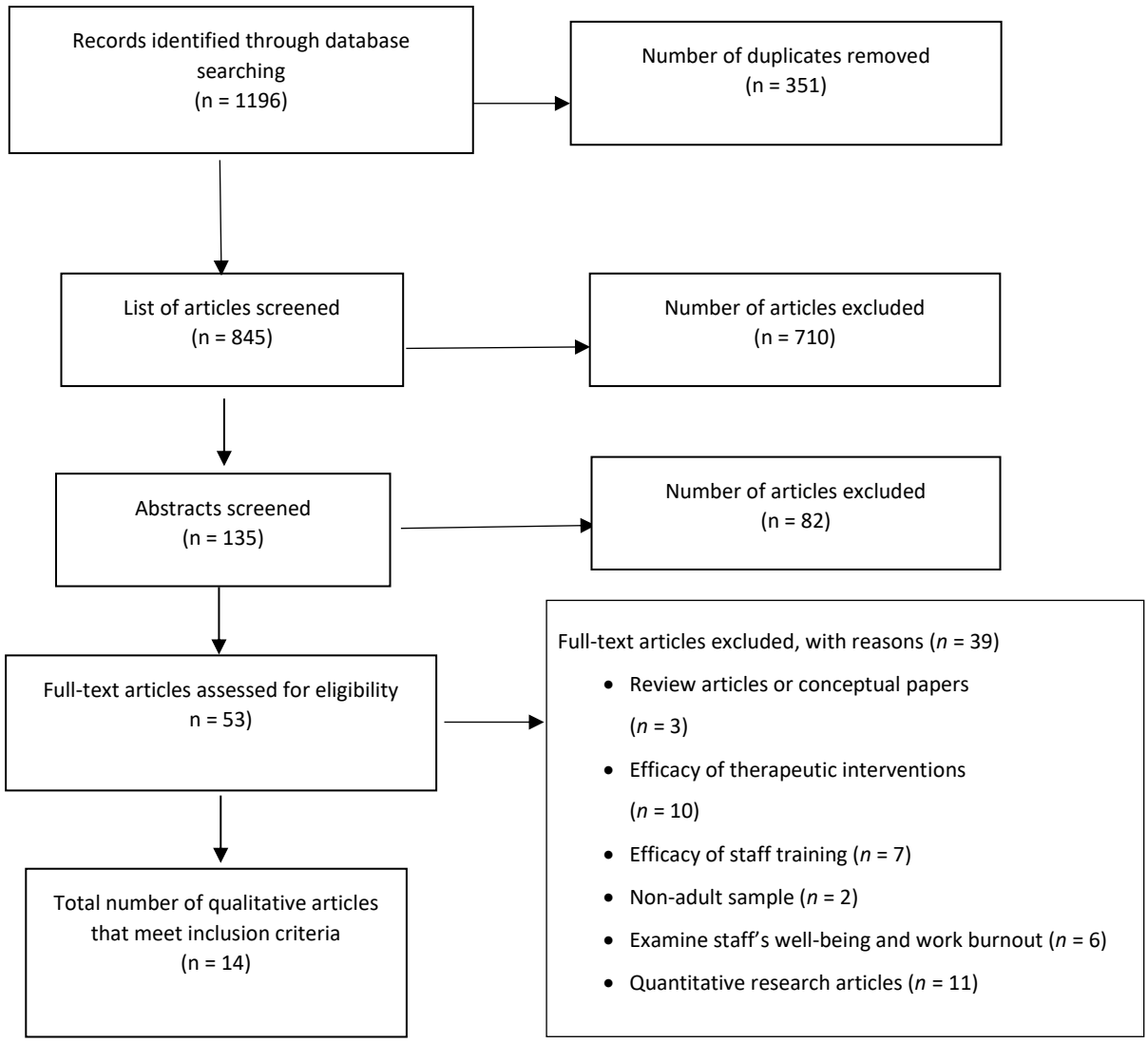
Inclusion Criteria	Exclusion Criteria
Sample consists of HCPs including medical staff, nurses, therapists, psychologists and social workers	Residential staff or HCPs working with residential/support staff
Must explore the experiences of HCPs working with people with ID and MH problems (e.g. providing services and/or care to them)	Explores experiences of HCPs or support staff working with people with ID (no MH problems)
English language qualitative studies	Describes services that provide care to people below 21 years of age
Published between 2006 – 2020	Exclude review articles, commentaries, book chapters or case studies

Search Strategy

The search terms were chosen and entered in the electronic databases as described in the Method section of Chapter 2 (Table 2.2, page 11) which resulted in a total of 1196 publications. These publications were screened taking into consideration only qualitative studies and 351 duplicates were removed, leaving a total of 845 publications. Publications that include other groups of participants such as carers, SUs and support staff were excluded. A further 710 publications were removed after reading the titles as they did not meet the inclusion criteria, leaving 135 publications. The abstracts of these publications were read and 82 articles were removing after failing to meet the inclusion criteria, leaving 53 publications. These 53 publications were further inspected by reading the main text and 39 publications failed to meet the inclusion criteria, leaving 14 studies for quality assessment.

The references of publications were examined to identify additional studies that met the inclusion criteria. None were identified resulting in a final total of 14 studies used for this review. Figure 3.1 presents a flow chart of the selection process for the systematic review.

Figure 3.1: Flow diagram of the qualitative review



Quality Assessment Tool

The quality of studies was evaluated and critically appraised by adapting the checklist from Cesario et al. (2002) and Mays and Pope (2000). This checklist was chosen because it offers a comprehensive range of criteria, such as examining the credibility, transferability, dependability and confirmability of qualitative research studies. The authors did not focus on any epistemological stance when developing this checklist and recommend it as suitable for healthcare-related research. The checklist consists of ten criteria and each criterion can be given a maximum score of 3 points if it is comprehensively addressed, 2 points if it is

adequately addressed or 1 point if it is poorly addressed. No points are awarded if the research study does not meet the criterion. The scores across the ten criteria are added to give an overall total score (maximum of 30).

For the purpose of this review, studies that scored a total score of 22-30 were awarded a rating of Gold; studies that scored a total of 15-21 were awarded Silver while studies that scored less than 15 were awarded Bronze.

Extraction of data for meta-synthesis

Meta-synthesis was used to develop super-ordinate themes across the selected qualitative studies because it was considered to be the most appropriate way of extracting and analysing reported themes across qualitative studies. The selected qualitative studies had similar research hypotheses that allowed for the use of meta-synthesis to derive and interpret the findings meaningfully. A type of meta-synthesis named meta-ethnography proposed by Noblit and Hare (1988) was chosen for the review because it does not prescribe any theoretical or epistemological stance during the synthesis of the studies, hence allowing different qualitative methodologies to be included while maintaining the integrity of the primary data. The synthesis was conducted at the level of themes rather than quotes, with themes being used to develop the overarching themes presented in this review. Table 3.2 shows the seven stages of the meta-ethnographic process.

Table 3.2: Seven stages of meta-ethnography from Atkins et al. (2008)

	Description of the stages
Step 1	Determining the research question
Step 2	Defining the focus of the synthesis by having an inclusion and criteria. After which, search for the relevant studies in the databases.
Step 3	Develop a quality assessment checklist to assess the quality of the studies. Read a couple of times to become familiar with the content and findings.
Step 4	Extract the emerging themes from the studies to create a list of emergent themes with relevant quotes. Analyse the emerging themes to check whether it is relevant to the research question and remove those that are not relevant
Step 5	Group the themes to relevant categories, compare the themes in paper 1 with paper 2 and so on with paper 3 to ensure that they remain relevant within each category
Step 6	Carry out third order interpretations by developing super-ordinate themes for each relevant category. Arrange the super-ordinate themes to form an overall narrative that answers the research questions with relevant quotes from the studies
Step 7	Write up and presentation of results for publication

Results

The results are presented under the headings: 1) Descriptive characteristics of the studies; 2) Quality Assessment and 3) Findings of the meta-synthesis.

Descriptive characteristics of the studies

This section provides a detailed description of the studies. The summary of the papers reviewed detailing the characteristics, findings, strengths and limitations can be found in Table 3.3. The studies included in this review will be referred to by the numbers allocated in this table.

Countries

Most of the studies reviewed were conducted in the UK (n=10). Single studies were conducted in South Africa, Norway, Canada and New Zealand.

Table 3.3: Summary of qualitative studies included in the review

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
1	Rose, O'Brien and Rose 2007) United Kingdom	To examine the views of healthcare professionals working in ID and MH services	Focus group	Grounded theory	29 healthcare staff members (20 females, 9 males) 21 HCPs had professional qualifications (15 mainstream staff, 10 specialist staff) Five nurses, one psychiatrist, eight psychologists, one occupational therapist, one speech therapist	**Definitions of mental health and learning disabilities** Diagnostic overshadowing, communication difficulties, what constitutes a MH diagnosis? **Staff competence and emotions** Feelings of inadequacy, training needs identified, feelings of intimidation, choosing to specialise in ID field **Current service delivery issues** Boundary issues, workload issues, medication or therapy, service user integration **Future service deliver issues** Specialist of generic services, need to maintain expertise, current generic services inadequate to incorporate this client group	Details of sample characteristics Details of the questions provided Independent analysis by multiple researchers	No reference or details regarding data saturation or reflexivity process Lacked description of techniques to establish credibility and trustworthiness of findings Lacked information regarding audit trail
2	Lunsky, Gracey & Gelfand (2008) Canada	To identify the issues and concerns dealing with people with ID and MH problems when they are admitted to emergency department (ER) in the hospital	Semi-structured interviews, focus groups	Content / thematic analysis?	44 hospital staff, including psychiatrists and psychiatry residents, nurses, social workers, and other crisis workers–allied health professionals (no information	**Description of Client Population** Issues that people with ID and MH problems faced that led him to visit ER, frequency of visits, time spend working with them during consultation and type of treatment used **Barriers–Challenges** Lacked knowledge and experience to work with this population, lack of understanding in the MH issues and services that they can	Detailed methodology with audit during data collection Explanation provided regarding the development of questionnaire Wide range of	Lack of details regarding the analysis. Lacked details of the sample characteristics Unclear qualitative theoretical

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
					about the breakdown)	refer them to in the communities, difficulties to communicate with caregivers and other service providers **Directions for Intervention** Having a less destressing place in the ER, improving interagency communication, having a resource lists, provide training to staff and caregivers	healthcare professionals sampled	framework used Lack discussion of implications in the discussion section
3	Hemmings, Underwood & Bouras (2009) United Kingdom	To compare the views of SUs, carers and healthcare professionals regarding the community services or support needed by people with ID and psychosis	Focus group	Content analysis (?)	Five specialist professionals (two females, three males with a mean age of 38.2) two psychiatrists, one nurse, one psychologist and one occupational therapist The rest are carers and SUs not included in the review	**Staff** Need training to increase competency **Treatment or interventions** Using and adapting various interventions to meet SUs' needs, communication with SUs to know more about their needs **Characteristics of service users** May require more intensive services, complex care required for high-risk SUs **Intensive service Components** lack of clarity between specialist vs generic MH services, lack of experience from professionals treating people with ID and psychosis	Clear details on the methodology Participants' characteristics were provided	Unclear on the choice of qualitative methodology used Lacked details on the analytic process Lacked details in describing the credibility and validity of the findings Possible researcher biases during analysis
4	McLaughlin, Taggart, Quinn & Milligan (2009)	To obtain the experiences and perceptions of healthcare professionals working with people with ID	Semi-structured interviews	Content analysis	13 healthcare staff (5 nurses and 3 social workers in ID settings, 5 mainstream staff) No information about age or	**Reasons people with ID turn to using illicit substances** Sub themes of vulnerability, loneliness **Assessment and treatment** Lack of formal assessment and protocols for intervention, unable to adapt interventions	Use of multiple researchers in analysis Clear details on identifying the	Lower response rate No discussion on the implications of the findings

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
	United Kingdom	and substance abuse and how their needs could be better met			experience	to engage with them **Skills and knowledge** No further education or specific training working with this population	topics for discussion Showed how the interview questions were developed	Lacked details on data saturation or reflexivity process
5	Taggart, McMillan and Lawson (2010) United Kingdom	To explore healthcare professionals' knowledge and perceptions of caring for women with ID and MH problems	Focused Group Interviews	Thematic content analysis	32 professionals (7 men and 25 women with age range from 26 to 57 years) 15 nurses, 10 social workers, 2 psychiatrists in specialist MH settings The others were support workers	**Risk factors** Identify factors that can increase the likelihood of the person with ID developing MH problems **Resilient/protective factors** Identify factors that increase the self-esteem of person with ID through promoting skills to help them cope with life demands **Barriers to accessing healthcare** Improve level of access for people with ID to seek mainstream healthcare services	Details of audit trail Analysis by different research and independent expert Clear objectives	Limited response from participants Lack details in implications of the findings
6	Storey, Collis & Clegg (2012) United Kingdom	To understand healthcare staff accounts of their work with people with ID and MH needs using psychoanalytical analysis	Free association interview	Psycho-dynamic analysis	Six nurses and 2 nursing assistants (Three females and five males aged between 20-50s) No other information was provided	**Emotional reactions** Negative experiences feelings, sense of powerless, feelings of uncertainty **Organisational issues** Little training or experience working with people with ID, lack of available manpower, difficulty managing patients with varying needs **Patient issues** Perceived being targeted by patients, such as emotionally and physically attacked	Details of reflexivity, keeping notes in journal Clear details of methodology	Lack details in data analysis and audit trail Details of sample were not provided Inconsistent procedures applied to participants

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
						Coping strategies Seeking to understand the reason behind their behaviour, displacement of negative emotions onto other things		
7	Campbell (2013) United Kingdom	To explore the experiences of nurses making sense of the violent incidents when taking care of people with ID and challenging behaviours	Semi-structured interviews	TA	Six registered nurses (No further details provided)	**Anticipation of violence** Constant potential for violence, anticipating violence to occur, feelings of distressed due to constant threat of violence **Emotional response of anxiety to violence** Feelings of anxiety, fear and vulnerability, stressed and scared following exposure to violence Perceived loss of control over their emotions when they became angry **Normalisation of violence** Repeated exposure of violence becomes part and parcel of the job **Social support** Discuss with other colleagues as a way to cope after violent incidents Reflect with colleagues how future incidents can be prevented **Extrinsic support** Lack of support from management to address staff's well being Perceive that the level of violence is accepted by management	Clear literature background Appropriate methodology to address the research question Appropriate details of procedure Appropriate use of quotes in the results section Strategies were put in place should participants became distressed	Sample size can be improved Lacked details regarding data saturation and participants' demographics No details regarding reflexivity or audit trail Information about the questions were not provided

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
8	Fredheim, Haavet, Danbolt, Kjønsberg and Lien (2013) Norway	To explore the experiences, attitudes and perceived role and competence of general practitioners providing health services to people with ID and MH problems	Semi-structured interviews	Systematic text condensation	Practitioners (GPs) Seven males and three females ranging from 41 to 64 years old	**Basic for decisions** Limited training, knowledge of the individuals' background and continuity in the physician-patient relationship provides best service **Consultations** Seeing the person at home, having someone who knows the person be present during visits **Treatment** Lack of confidence that a specialist would do a better job, fears specialist health services would reject the referral **Evaluation and continuing treatment** Challenges in reviewing medication, unsure of attending interdisciplinary meetings	Provides detailed summary of participant characteristics Discussion of implications of clinical practice Provide information about the questions used during the interview	Lacked details on the choice of theoretical framework for analysis No reference to data saturation Lacked information about credibility checks
9	Stenfert-Kroese, Rose, Heer and O'Brien (2013a) United Kingdom	To investigate healthcare professionals and SUs' views of gender differences in cause and presentation of MH problems in people with ID and whether they are any differences in the way the current services respond	Focused Group and semi-structured Interviews	TA	<u>Focus Group</u> 16 staff including healthcare professionals (10 females and 6 males) Two nurses, one social worker, three psychologists and one counsellor. The rest are support staff <u>Interviews</u> 10 healthcare	**Compliance vs challenge** Women are more likely to comply while men have a tendency to challenge **Vulnerability** Women are more vulnerable to abuse while men are more likely to experience addictions **Expression of emotion** Women are more likely to express their anxieties and talk more about their MH problems **Differences in staff treatment in men and women**	Provided clear details on methodology Clear aims with support from relevant literature Details of audit trail and analysis by multiple researchers	Lacked discussion on the reflexivity during analytic process

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
		relating to gender			professionals (7 females and 3 males with average age of 43). Five nurses, four social workers and one psychologist	Equality, same-sex support, boundaries		
10	Stenfert-Kroese, Rose, Heer and O'Brien (2013b) United Kingdom	To explore experiences of healthcare professionals and SUs regarding the provision of MH services and suggestions to improve the delivery of services	Focused Group and semi-structured Interviews	IPA	<u>Focus Group</u> 16 staff including healthcare professionals (10 females and 6 males) Two nurses, one social worker, three psychologists and one counsellor. The rest are support staff <u>Interviews</u> 10 healthcare professionals (7 females and 3 males with average age of 43) Five nurses, four social workers and one psychologist	**Desirable staff qualities** Being interested, communication styles and techniques, competence promoting support, awareness of link between past, present and future **Good quality services** Prevention, Regular reviews and liaison, working with care, looking after staff, staff training/supervision, Interface between services	Provided clear details on methodology Clear aims with support from relevant literature Details of audit trail and analysis by multiple researchers	Limited discussion on the limitations of the findings Purposive sample

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
11	Capri & Buckle (2015) South Africa	To examine the challenges faced by nurses taking care of people with ID and MH problems and suggestions to address these care challenges	Free association narrative interview	TA	13 females and 3 males nurses with a working experience ranging from 3 to 30 years	**Relational interaction** Fulfilment, reciprocity, meaningfulness, pride in their work, noble self-perception **Care burden** Difficult to care for, trying to reduce self-injury behaviours, encountered episodes of violence and assault, feelings of fear, constant vigilance, powerlessness, ward as work environment, lack simulating work, invasion of personal boundaries, adjusting to work environment, negative stigma working in this field **System fatigue (organizational factors)** Heavy workload, mental and physical depletion, critical staff shortage, chronic staffing issues, staff inadequacy **System fatigue (lack of organizational support: little care for the carer)** Feeling abandoned, exploited, unacknowledged, devalued, marginalized, scapegoated, judged, unheard regarding patient care requirements, embattled, disregarded, disrespected, unappreciated by other HCPS, emotionally exhausted, depersonalized **Infantilising dynamic of care** Treating people with ID as children, mother-child bond, lack empowerment in people with ID, inadequate preparation during	Participant involvement in verifying the findings as a validity procedure Details about consent-taking process Relevant literature background to support research aims Details about the audit trails Details about participants' characteristics	Possible gender biases in participants' responses No details on how the translation process during the transcription of data

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
						formal training, limited opportunities for further training **Resources for coping** Internal and external sources, taking leave, designated counselling, reliable reciprocated and functional support		
12	Lee & Kiemle (2015) United Kingdom	To examine the experiences of nurses working with people with ID and personality disorder	Semi-structured interviews	IPA	Two male and seven female qualified intellectual disability nurses with a mean age of 42 and worked for an average of 9.3 years. Work experience ranged from 14 months to 2 years	**Disorder overriding disability** Negative traits attributed to MH problems, difficulty forming meaningful therapeutic relationships, need for structure, challenges attributed to MH problems **Resilience** Focus on the positive, emotionally distant from clients, difficulty to care for them at times **Seeing the person behind the label towards label** Consequence of label, gender differences in attribution of behaviours **Knowledge** Having lack of training, importance of knowledge, level of understanding increased over time	Clear references to credibility and triangulation checks Themes are well-described with relevant quotes Details about the reflexive practices and audit trails	Brief details of sample Details of the interview schedule were not provided Unclear whether the participants were debriefed
13	McNally & McMurray (2015) United Kingdom	To investigate the experiences of psychologists towards people with ID accessing mainstream MH	Focus groups	TA	Two groups of participants – 4 psychologists in MH team and 5 psychologists in ID team (no further information is	**Themes from mainstream MH services** **Service restrictions** Lack of appropriate structure and resources, overwhelming service demands, developing specialist MH service **Confidence in ability**	Use of appropriate methodology Applying credibility checks during the analysis phase	Lacked information regarding missing data and data saturation Lacked details

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
		services			provided)	Feelings of anxiety, lack experience, need for supervision **Resistance to change** Limited outcomes in mainstream services, preference for people with ID to access specialist services, wants more autonomy in their work with people with ID **Themes from specialist ID** **Future thinking** People with ID having a right to access mainstream services, help people with ID to understand their rights, providing clear pathways for them to access mainstream services **Protection** Being protective towards people with ID, perceive that mainstream staff does not want to work with this population **Pessimism** Mainstream MH service not willing to make necessary adjustments **Clarification around MH and ID** Influence of diagnostic shadowing		about audit trails Lacked description of participants' characteristics Possible biases from researchers during analysis
14	Taua, Neville and Scott (2017)	To explore how nurses utilize their skills caring for people with ID and MH problems in inpatient MH	Semi-structured interviews	TA	13 nurses (9 females and 4 males with average age of 45 and 18.46 years of work	**Contextualizing behaviour** Having the skill to recognise challenging behaviour, manage risk-related issues and provide opportunities for people with ID to learn how to manage their behaviour	Details of sample characteristics Include details of interview schedule	Lack details of audit trail Sampling response bias

No	Author (Year) and country	Aims	Data Collection	Data Analysis	Participants	Themes	Strength	Limitations
	New Zealand	settings			experience	**Communication** Having effective communication strategies when interacting with person with ID **Confidence to care** Having an in-depth knowledge improves staff's confidence to care for person with ID **Time** Having adequate time to work effectively to support people with ID as well as gaining additional experience	Clear methodology and aims	Lack reflexivity Nothing was mentioned about informed consent and confidentiality of the data

Participants and settings

The sample sizes of the studies ranged from 5 to 44 (median = 13) and included 196 HCPs in total. The rest of the participants were support staff, SUs and FCs who were not included in this review. Five studies did not provide further information on the characteristics of the participants (Studies 2, 3, 4, 6, 13) while the rest provided detailed descriptions such as age, gender and amount of work experience. Studies 6, 7, 11, 12 and 14 solely recruited nurses as their sample (37 specialised MH nurses and 13 mainstream nurses), Studies 8 and 13 recruited psychologists (4 mainstream and 5 specialised) and general practitioners (n=10) respectively as their sample. The rest of the studies employed a mixture of HCPs with varying specialisations such as psychiatrists (n=5), nurses (n=42), psychologists (n=12), medical social workers (n=20), speech therapists (n=3) and occupational therapists (n=4). Study 2 did not provide the breakdown of the participants' professional background. Studies 1, 4 and 13 had a mixture of participants working in mainstream and specialised MH settings. Studies 9 and 10 used the same pool of participants but were asked different questions based on the objectives of the two research studies and the data obtained during the interviews were analysed and reported separately.

A number of different recruitment strategies were used across the fourteen studies, the majority of them recruited participants from hospital or inpatient settings (n=7). Out of the seven studies, four included participants working in inpatient specialist services (Studies 6, 7, 11 and 12), two recruited from mainstream inpatient services (Studies 2 and 14) and study 13 recruited from a mixture of mainstream and specialised settings. Three studies recruited participants from community services (Studies 3, 4 and 8). The rest of the studies (Studies 1, 5, 9 and 10) recruited participants from hospital and community settings. Most studies

employed purposive sampling and used an information letter or word-of-mouth to recruit participants.

Methodological approaches

Five of the studies used semi-structured interviews, three studies used a mix of focus groups and interviews and four studies used solely focus groups. The remaining two studies used free association narrative interviews. Most of the studies provided additional information on the questions used to guide the interviews (Studies 1, 2, 3, 8, 9, 10, 11, 13 and 14).

The qualitative approach utilised by seven studies was TA (Studies 4, 5, 7, 9, 11, 13 and 14), followed by IPA (Studies 10 and 12), content analysis (Study 4), TA with a psychodynamic theoretical framework (Study 6), systematic text condensation (Study 8), grounded theory (Study 1) and two did not specify any approach (Studies 2 and 3). Studies 5 and 14 employed computer software to assist in the generating the themes.

Quality Assessment

Four of the studies (Studies 9, 10, 11 and 12) stood out for having attained the highest (Gold) quality standard. These studies have a detailed background literature, clearly defined hypotheses, appropriate explanation of the use of the methodology to collect the interviews and a detailed explanation of the analysis process to develop the themes. Studies 9, 10 and 12 audited the transcripts and kept a reflective journal to bracket researchers' subjective views which reduced the interference of their personal presumptions or beliefs during the analysis.

The majority (N=9) of the studies were categorised in the moderate (Silver) category. These studies provided brief description of the sample size and aims of the study. Some of them

did not provide a detailed description of the audit trail or explained the rationale for choosing the particular epistemological stance for analysis. Some studies did not take into account the prior researcher-participant relationship (such as co-workers) that may influence the analysis and results. Study 2 consulted participants to verify the accuracy of the transcripts and the interpretation of the results.

Study 3 was placed in the poor (Bronze) category because it lacked a detailed description of the sample size, objectives and aims of the study. There was no information regarding the type of analysis used and lacked details about how the data were collected.

All the studies used quotes to support their findings and interpretation of the results. Study 5 had an independent expert to verify the findings of the study. Most of the studies carried out separate analyses by different researchers before coming together to consolidate and agree upon the themes. There was a lack of information regarding how the finalised themes were agreed upon. Other limitations of these studies include a lack of detailed information regarding how the researchers reached data saturation, lack of consideration of the researchers' personal biases or how their professional background may have affected the interviews with participants and a lack of explanation of how these issues were addressed during the analysis process. Table 3.4 shows the ratings for each study.

Table 3.4: Quality assessment of qualitative reviews

STUDY NO	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Assessment Criteria	**Rose, O'Brien & Rose (2007)**	**Lunsky, Gracey & Gelfand (2008)**	**Hemmings, Underwood & Bouras (2009)**	**McLaughlin, Taggart, Quinn & Milligan (2009)**	**Taggart, McMillan & Lawson (2010)**	**Storey, Collis & Clegg (2012)**	**Campbell (2013)**	**Fredheim, Haavet, Danbolt, Kjønsberg & Lien (2013)**	**Stenfert -Kroese, Rose, Heer & O'Brien (2013a)**	**Stenfert -Kroese, Rose, Heer & O'Brien (2013b)**	**Capri & Buckle (2015)**	**Lee & Kiemle (2015)**	**McNally & Murray (2015)**	**Taua, Neville & Scott (2017)**	**Mean score for each criterion**
Clear statement of aims/objectives of the research with supporting evidence from literature	2	2	2	3	3	2	3	2	3	2	3	3	3	2	2.5
Appropriate and clear research design (qualitative) relevant to the research aims/hypotheses	2	2	2	2	3	3	3	2	3	3	2	3	3	3	2.6
Detailed description and discussion of the methodological procedures	3	2	2	1	2	3	2	2	3	3	3	3	2	3	2.4
Appropriate sample selection that address the aims with detailed description of sample characteristics	3	1	2	1	2	1	1	3	3	3	3	2	1	3	2.1
Clear details of data procedures (e.g how data was collected, instruments used and discussion of data saturation)	3	2	1	2	2	2	2	2	2	2	3	2	2	2	2.1

Evidence of reflexivity described (e.g consideration of researcher-participant relationships, personal biases)	0	1	0	0	1	2	1	0	1	2	0	3	0	0	0.8
Details of ethical consideration (e.g getting ethical approval, informed consent, confidentiality and possible effects on participants)	1	2	2	2	2	2	3	1	2	2	3	2	1	1	1.9
Evidence of audit trail with clear description of data analysis (e.g details of theoretical framework)	1	1	0	1	3	1	1	1	2	2	2	2	2	0	1.4
Findings are supported by data using quotes. Use of techniques to establish credibility and trustworthiness of data	2	2	1	2	2	2	2	2	3	3	3	3	1	2	2.1
Clear statement of findings that demonstrate relevance to current clinical practice and increases knowledge in the literature	3	2	1	2	2	2	1	2	3	3	2	3	2	2	2.1
TOTAL	20	17	13	16	22	20	19	17	25	25	24	26	17	18	
RATING	**SILVER**	**SILVER**	**BRONZE**	**SILVER**	**SILVER**	**SILVER**	**SILVER**	**SILVER**	**GOLD**	**GOLD**	**GOLD**	**GOLD**	**SILVER**	**SILVER**	

Meta-Synthesis Findings

Table 3.5 shows the three main themes that were identified which were 1) Understanding the person with ID and MH problems; 2) Relational interaction between healthcare professional and the service user; and 3) Organizational factors. The first and last themes consist of two subthemes while the second main theme consists of three subthemes. The quotations from the participants in the studies are presented in italics whereas the quotations from study authors are not italicised.

Table 3.5: Synthesis of themes on HCPs' experiences of working with people with ID and MH problems

Main themes	Studies that contribute to the themes/sub-themes	Sub themes
1, Understanding the person with ID and mental health problems	1, 2, 3, 4, 5, 10, 12, 13 and 14	i. Identifying mental health problems ii. Complexity of mental health problems
2. Relational Interaction	1, 4, 8, 10, 11 and 14	i. Communication
	1, 2, 4, 6, 7, 8, 10, 11, 12, 13 and 14	ii. Emotional reactions
	2, 6, 7, 11, 12	iii. Care burden
3. Organisational factors	1, 2, 4, 6, 7, 9, 10, 11 and 13	i. Perceived support ii. Recommendations to improve services

Main theme 1: Understanding the person with ID and mental health problems

This theme describes how HCPs develop an understanding of the adult person with ID in a holistic manner while at the same time identifying the individuals' MH problems during the assessment or the initial phase of care.

Sub-theme 1: Identifying mental health problems

Participants recognised that adults with ID had a higher prevalence rate of MH problems and that FCs often did not seek help from HCPs until they are unable to manage (Studies 1, 2, 3, 4, 5, 10, 12, 13 and 14). Participants noted that the behaviours of the person with ID became the main focus of treatment where FCs looked for a cure to eliminate the behaviours or transfer the burden of care to them,

> *"They* [the carers] *bring the patient to the ER looking for a miracle pill or wanting the hospital because they can't cope." (Study 2, p. 449)*

> *"It's not usually evident what the mental health issue is. It usually seems to be there's been a crisis in behaviour." (Study 14, p. 633)*

Participants acknowledged that HCPs sometimes attributed the behaviours of the person with ID to the ID diagnosis and failed to recognise that these behaviours might represent underlying MH problems that required treatment,

> *"I think people just look at it all together really, they think it's just challenging behaviour, they don't think about the mental health issues." (Study 1, p. 55)*

Other participants recognised that MH problems in adults with ID may be manifestations of other problem behaviours, such as substance abuse or self-harm, caused by previous exploitation, sexual abuse or due to social circumstances such as feeling a sense of loneliness with lack of adequate social support,

"Again a lot of physical problems, maybe presenting to casualty, overdosing, self-harming, just self-neglect again, one or two of them are very vulnerable and I feel that a lot of them have maybe been exploited, financially and query sexually." (Study 4, p. 136)

Participants reflected that they needed to *"take the time to know each client",* hence spending more time *"getting to know each client on an individual basis" (Study 10, p 6),* trying to identify different behavioural issues and assess whether they were MH related or part of the individual's ID,

"It's a matter of trial and error, trying things, what worked, what doesn't work, trying to find certain key words of certain key phrases...it's important to take the time to listen, taking the time to observe, trying things, failing…learning from those mistakes." (Study 14, p. 636)

Likewise, participants described the assessment process as requiring extensive resources and time, especially when there were challenges in obtaining relevant information before they could formulate and carry out their treatment plan,

"Assessments require collateral information, but often there is little, which makes the assessment hard. It's a lot of legwork to gather history." (Study 2, p. 450)

This was particularly difficult for participants working in mainstream setting because of the high service demands, *"We're obviously swamped and the more people we can keep out the better" (Study 13, p. 355)* and the lack of resources available in mainstream services,

"But you really do need much more resources – lots of visual cues and lots of, just anything that you need. And I'm just like, where would you even get that…?" (Study 13, p. 355)

The benefits of having extra time during the assessment helped HCPs to conduct a comprehensive assessment to get to know the individual with ID and understand how their previous life experiences had led to the development of their MH problems and identified positive characteristics in the person with ID,

> *"They've all got their own special qualities, when you actually see the person, not the personality disorder and not the learning disability." (Study 12, p. 243)*

Sub-theme 2: Complexity of mental health problems

This sub-theme describes the complexity of MH problems that participants encountered when working with adults with ID, describing the assessment phase of the treatment, *"it's like peeling an onion" (Study 2, p. 450)*, is to discover the different underlying risk factors that contribute to the complexity of the MH problems and the challenges adults with ID face in their daily life that contributed to their negative feelings and poor coping strategies,

> *"I have a few women who definitely use alcohol as a coping mechanism. They struggle with the expectations placed on them and they don't see themselves as meeting these expectations, therefore they are depressed and lonely, using the alcohol to give them a reprieve and a release from feeling that way." (Study 5, p. 95)*

Study 12 identified feelings of frustration that the participants sometimes *"struggled to get past" (p. 249)* when they were unable to make any progress working with adults with ID and led them to conclude that the MH problems in this population were negative personality traits or attributions which were *"fixed and cannot be improved" (p. 249).*

Specialist ID staff noted that the MH problems in people with ID may develop due to past negative childhood experiences, *"I think behind a lot of mental health presentations, there's*

a childhood experience of being bullied or disenfranchised in some way from normal life" (Study 13, p. 357) and often were not addressed due to the presence of the ID diagnosis,

> *"Most people that we see have a learning disability have a mental health problem, but actually, when I think, a lot of them don't have a diagnosis" (Study 13, p. 357)*

While participants acknowledged difficulty in distinguishing MH problems from the ID diagnosis, they expressed hope that other HCPs will try to contextualise the MH problems or redefine them to create a better understanding of the individual,

> *"I think once they could see that it was actually within the context of a psychotic episode then what I hope to see is that they will actually treat the person in the same way as they would someone else." (Study 14, p. 633)*

Given the complexity of MH problems in adults with ID, participants agreed that medication, such as clozapine and benzodiazepines, were often used as *"the first line" (Study 1, p. 56)* before considering other non-pharmacological approaches to manage the symptoms,

> *"Family interventions... the family or carer support to understand the illness. the drugs... the side effects, how to spot relapse, how to support someone if they're hearing voices." (Study 3, p 24)*

However, there were some occasions where participants lacked the knowledge of non-pharmacological treatment, *"…what is the level of understanding for CBT…?" (Study 1, p. 56)*, or shared about past experiences where they had encountered some of their clients who were only offered medication,

> *"We have a girl who is now on anti-depressants because she lost her mother... there is no counselling, there is nothing, basically just medication and that's it." (Study 5, p. 96)*

Main theme 2: Relational Interaction

This second theme relates to how HCPs viewed their role of providing treatment and services to adults with ID and MH problems as a "deeply emotional, intimate relationship" (Kittay et al., 2005, p. 444), finding a sense of fulfilment in the therapeutic relationship with this client group, being actively involved in providing treatment and engaging with them during the intervention process.

Sub-theme 1: Communication

Participants in seven of the studies described challenges in communicating with people with ID and MH problems (Studies 1, 4, 8, 10, 11 and 14). The findings in these studies described participants requiring specialist communication skills when interacting with this population and the challenge to establish therapeutic relationships with adults with ID,

> *"Hospitals have million-dollar machines that everyone has to be skilled at using, and you get to mental health and then include intellectual disability...and our only real tool is our communication. That is it...as long as you are confident, you can get somewhere with the ID person." (Study 14, p. 634)*

Participants expressed uncertainty about being able to overcome communication difficulties, especially when providing explanations about the treatment process,

> *"The hardest part is communication, getting yourself across in the right manner." (Study 1, p. 55)*

Participants in study 11 attuned themselves to the communication needs of people with ID through *"reading body language(s) or by familiarity with their personality" (p. 176).* It was noted that the development of rapport does not need to solely rely on the use of verbal communication, other forms of non-verbal communication can also be used,

"A lot of experience I had was...using pictures and diagrams and just learning to actually think quite laterally about how can you explain things in quite a basic way…explain something in a way that is empowering and not patronizing." (Study 14, p. 634)

Their relationships with clients sometimes affected the participants emotionally when they viewed themselves as a parental figure, *"I grew attached quickly...I'm a mommy at work; I came to love them, they are my children…" (Study 11, p. 176)* and became sad when their client was discharged from the services,

"We have to prepare them for the community, but when they go...I am very sad...I have to walk away." (Study 11, p. 176)

Sub-theme 2: Emotional reactions

All of the studies, with the exception of studies 3, 5 and 9 highlighted the emotional reactions that participants experienced when working with adults with ID and MH problems. Participants in study 11 shared that they *"feel proud"* and *"enjoy doing the work"* despite acknowledging that *"it is not easy working"* with this population, reflecting a *"noble self-perception" (p. 173)* in their job of providing services and care to someone with high care needs and MH problems.

However, participants in other studies reported on the fluctuating intensity of emotions when working with adults with ID and MH problems, and described it as a difficult task,

"It's one of the hardest jobs in the world. And it was like a roller coaster ride. Erm, and sometimes you'd find it really overwhelming." (Study 12, pp. 242)

Feelings that participants reported also included anger, high levels of anxiety and stress when exposed to violence,

"Stressed and quite scared sometimes, sometimes angry that we should be exposed to this – it is a mixture really." (Study 7, p. 44)

In addition, feelings of intimidation and being scared, *"It's still quite scary" (Study 13, p. 355),* were reported when participants lacked the confidence to provide high quality services often due to inexperience, training and knowledge,

"I have quite a few on my books, just on that borderline and I do feel like I'm failing them." (Study 13, p. 355)

"I don't know whether it's actually training but some kind of awareness sessions or some to staff in feeling less intimidated maybe because I think a lot of it is that they [the staff] feel intimidated." (Study 1, p. 56)

At times, participants expressed feelings of vulnerability and inadequacy as a result of emotional fatigue, often exacerbated by repeated exposure to violence or increased workload that affected the therapeutic relationship with adults with ID,

"It makes me feel, not all the time but it does make me feel vulnerable and sometimes I must admit I have actually thought 'what am I doing here', 'why am I doing this' and then I think about it." (Study 7, p. 44)

"Sometimes it feels so overwhelming. You get tired, working long hours. Nobody supports us. When something happens in a ward...the nurses are pushed down." (Study 11, pp. 174-175)

Sometimes, participants experienced feeling alone because of their lack of experience, especially when faced with challenges and no clear avenues to seek help,

"I feel really alone on this topic with these patients. I don't really know what to do." (Study 8, p. 5)

Sub-theme 3: Care burden

Many participants described having negative experiences of being verbally or physically targeted when working with adults having ID and MH problems, affecting their sense of motivation to continue working in this field,

> *"She'd also know things that pushed my buttons. … that was really tiring, 'cos she would just be on you and you knew, you'd trip up before she would if you weren't careful 'cos she was that good at it … she'd have a subject that she knew I couldn't, I wouldn't, I was weak on and she'd always manage to trip me up …." (Study 6, p. 232)*

In addition, participants described difficulty in forming meaningful therapeutic relationships due to the nature of the MH symptoms in adults with ID and preferred to remain emotionally distant,

> *"The symptoms, if you like, of personality disorder make you a lot more wary of developing a relationship, yep, erm, yea again, you're kinda a lot more suspicious!" (Study 12, p. 242)*

The threat of violence was something that participants had concerns about, knowing that there was always the potential for violence when working with some adults with ID,

> *"Every day when you walk on a shift or when you walk onto the unit until you know what is actually happening you need to be aware that it [violence] can happen at any time…" (Study 2, p. 43)*

> *"One moment it's a block to play with, the next you get thrown with it"; "This client just grabbed a chair and threw me with [it]." (Study 11, p. 173)*

Working with people with ID and complex MH problems can be a tiring and draining experience,

"It can be quite tiring cos obviously, a lot of the behaviours are repeated, over and over, and that's quite frustrating. It can feel quite hard cos you don't seem to move on from things and move forwards." (Study 12, p. 241)

Participants viewed themselves for being "*weak*" and blamed themselves when their clients made them upset,

"She'd also know things that pushed my buttons. … that was really tiring, cos she would just be on you and you knew, you'd trip up before she would if you weren't careful 'cos she was that good at it … she'd have a subject that she knew I couldn't, I wouldn't, I was weak on and she'd always manage to trip me up …." (Study 6, p. 233)

Participants had developed coping strategies to manage stress by focusing on the positive characteristics or resilience traits of the person with ID, sharing their negative feelings or experiences among their colleagues as well as focusing on positive experiences of their work,

"I try not to be pessimistic … and look at it positively." (Study 6, p. 231)

Some participants expressed the need to have a designated MH professional from whom they could seek professional help,

"It would have been nice to know that there would be someone...if I'm having these feelings that I'm bottling up...I can go talk to. We don't have that." (Study 11, p. 177)

There were some who preferred not to discuss any emotional impact or feelings of vulnerability and helplessness because they perceived that expressing such feelings was forbidden, *"You're not supposed to say things … like that but no." (Study 6, p. 233).*

Main theme 3: Organisational factors

The final theme described the organisational barriers and support that HCPs encountered when working with adults with ID and MH problems as well as their views and recommendations to improve the MH services.

Sub-theme 1: Perceived support

This sub-theme describes the support that HCPs received in their workplaces when working with adults having ID and MH problems (Studies 1, 2, 4, 6, 7, 9, 10 and 11). Participants identified how increased workload as a result of unnecessary administrative procedures and staff shortages affected their morale, making them feel disempowered and meaningless, and added stress when they were unable to do their job satisfactorily (Study 6, p. 232; Study 10, p. 9). They generally agreed that heavy workload and long working hours could lead to emotional fatigue, *"Sometimes it feels so overwhelming" (Study 11, p. 174),* often resulting in stress-related symptoms and having less time to spend with family, leaving them feeling exploited and unappreciated,

> *"You get tired, working long hours, when you get home, you don't really have time for your family, you just want to get in the bath and into bed."*
> *(Study 11, p. 174)*

> *"They properly exploit me, I sometimes feel so abused... like floor polish."*
> *(Study 11, p. 175)*

Participants reported that their managers often did not support them and lacked empathy to address their concerns. For example, managers could be seen as unresponsive to the emotional impact of violence in the workplace, which could increase feelings of powerlessness,

"There is sort of a feeling that we are not supported enough because . . . I think management have got this idea that there is a certain threshold/tolerance level for violence in the workplace that has almost become acceptable. So I often feel... we don't get the support that we should be getting." (Study 7, p. 44)

Forms of valued support include teamworking and multidisciplinary collaboration with other HCPs. However, participants also described the challenges of working with other HCPs when they considered that their role and specialist set of skills were not always valued, hence perceiving that their opinions were not important enough to be taken into consideration during multi-disciplinary meetings,

"Sometimes [the doctors are] very nasty... they criticise. The nurse's voice is not always so important unless it's the doctor... if it's a nurse who sees there's a need then they won't jump to help you." (Study 11, p. 175)

In contrast, participants valuing the input and advice from various specialist HCPs, recognising that good teamwork can deliver consistency of approach to improve the care of the person with ID and MH problems, *"… everyone sings from the same song sheet, so to speak" (Study 10, p. 8).*

Further areas of support that participants found lacking in their workplace was the lack of training and supervision to improve their clinical practice and increase their knowledge of the dual speciality of ID and MH. Most participants considered additional training to be an important component as part of their job, *"People should have the right training for the job so they can do their job properly" (Study 10, p. 9-10)*, and requested additional formal training or supervision from SHCPs to learn skills in communicating with people with ID,

"How can I engage with this person? We don't have that expertise. Dual diagnosis is not something mental health staff have skills or experience with." (Study 12, p. 449)

"Intellectual disability nurses have the skills for communicating and working with people. Other people have the skills of dealing mainly with drugs and alcohol; [mental health problems], you know a combination of both skills would be advantageous…" (Study 4, p. 139)

Some participants preferred having informal training, such as gaining experience and learning on the job with supervision, to develop their expertise over time,

"…you learn very quickly on the job sort of thing and develop skills over time." (Study 1, p 56)

"Well, now I've got supervision with somebody else so, it's a lot better…" (Study 10, p 10)

Sub-theme 2: Recommendations to improve services

Participants reported that their current service delivery did not address the need for early detection of MH problems for people with ID. They spoke about the lack of coordination between different services in the community and tertiary settings where there was a lack of knowledge regarding where adults with ID and MH problems could seek help,

"The system is fragmented. We don't know what's out there and it's hard to navigate." (Study 4, p. 450)

There was an agreement among participants that the current mainstream MH services were inadequate and not meeting the needs of people with ID, which resulted in poor outcomes for adults with ID and MH problems,

"I don't think our service is geared up to be sympathetic to a client group that might be struggling with the confidence to actually say, oh yes I could

get myself to wherever to see this psychologist on my own…" (Study 1, p. 57)

Recommendations to improve access to MH services include additional training for MHCPs where they may come across adults with ID in emergency departments for hospital admission or being allowed to have more resources such as time to do their job,

"… people with intellectual disabilities being placed with [psychiatric] hospital staff that haven't got the knowledge to work with them or might even find it quite frustrating to work with somebody with a learning disability if they haven't done before…"(Study 10, p. 11)

"I most certainty think I would be able to do it if I was allowed more time to think and more space to think." (Study 13, p. 355)

In addition, some participants considered whether establishing specialist services where they did not exist previously would improve the quality of care for people with ID and MH problems while others considered that having a specialised service would go against their right to access mainstream MH service,

"I would say a specialist team… you do need something specific and the whole thing with the consultant on board as well, the whole package." (Study 1, p. 57)

"From an equality point of view, it would be difficult to argue anything but that they have a right to access the mainstream adult mental health setting." (Study 13, p. 357)

Existing collaboration between community services, primary healthcare settings and tertiary mental healthcare teams that comprised of HCPs with differing specialities and experiences was seen as a positive way to access appropriate services,

"Having skills in alcohol and drugs [mental health problems], and also somebody knowing how to work effectively with people with intellectual disability, or a link person, could draw up some sort of a joint strategy between both services that would help the client to get the right service." (Study 4, p. 139)

"If I wanted to refer a patient with these problems, NN was the person. NN, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions." (Study 8, p. 5)

Participants recommended that more resources should be tailored to increase accessibility of mainstream services to people with ID where they could receive support to address their social needs,

"I think it's about helping them access the generic services especially the housing… and substance misuse and employment." (Study 3, p. 26)

There were several suggestions to reduce the barriers of access to MH services for adults with ID, for example having a *"health promotion literature in a user friendly format"* that includes a *"resource list of available services, including a website and a 24-hr telephone line" (Study 5, p. 97; Study 2, p. 449)* for FCs and having access to HCPs of the same gender for highly complex cases, such as cases of domestic and sexual abuse (Study 9, p. 187).

They also recognised the importance of using screening tools in mainstream MH services or primary care health settings to detect early signs of MH and/or challenging behaviours so that people with ID could be referred to appropriate services for a more comprehensive assessment and treatment (Study 13, p. 96). They also recommended that HCPs with both expertise in ID and MH were made more available at the mainstream settings to provide education and training to mainstream professional staff (Study 7, p. 129).

Discussion

This paper focused on the experiences of HCPs when providing MH services for adults with ID and MH problems. Findings of the meta-synthesis identified three main themes: (1) developing an understanding of the person with ID and MH problems; (2) therapeutic relationship and interactions with people with ID when working with them and lastly (3); organisational barriers and recommendations to improve the MH services to this specific population. Of the fourteen studies included, four were rated to be of good quality (Gold), nine were rated to be of acceptable quality (Silver) and one was rated to be of poor quality (Bronze). Most of the selected studies demonstrated clear research aims or objectives with appropriate research design and provided rich details of the methodology. However, reflexivity and audit process were lacking and/or less well described, for example not considering the personal views and biases of the researchers or ensuring that the findings were validated with the participants. One paper was rated Bronze because of the poorly described research design and lack of clarity in the analysis. Some of the themes from that paper carried less weight, nonetheless, there were some themes that replicated findings of some of the stronger studies and these were extracted for the meta-synthesis.

HCPs identified MH symptoms in adults with ID and recognised that these symptoms were sometimes misattributed to the diagnosis of ID and not promptly treated. Reiss et al. (1982) termed this misattribution bias as diagnostic overshadowing where HCPs tend to ignore or overlook the MH symptoms and consider them to be part of the ID diagnosis. The findings indicate that diagnostic overshadowing may influence the treatment of adults with ID and may lead to negative perceptions or stigmatising attitudes towards them among HCPs (Jopp & Keys, 2001).

Due to the complexity of MH problems, HCPs reported taking longer and needing more resources when working with people with ID, which they did not often have, especially when working in mainstream services. As a result, they were overwhelmed and unable to understand the MH needs of people with ID and to consider behavioural strategies to manage their behaviours. Hence, HCPs acknowledged that psychotropic medication are often used as primary treatment method to reduce or eliminate the MH and/or challenging behaviours without consulting and/or training FCs to identify and change the environmental triggers to minimise severity of those behaviours. The social care needs (such as housing, social relationships and daytime activities) in people with ID are not adequately addressed when people with ID seek MH services (Strydom et al., 2005), likely because of constraints within the MH services to address those social needs as well as the poorly planned transition between services and lack of coordination with other agencies (Wei et al., 2012). Another possible explanation is that HCPs view the MH problems from a medical treatment model perspective and consider the 'problem' to lie with the person with ID for being unable to adjust to their environment (Williams & Heslop, 2005). This may explain the feelings of frustration in HCPs when they struggle to make progress and leading them to view the MH problems as untreatable.

The themes regarding HCPs experiencing struggles in their work, communicating and interacting with adults with ID, highlight the inadequacies in the knowledge and training they have received. Studies have explored the effectiveness of training for staff to increase their understanding of MH issues of people with ID and found an increase in their level of confidence and knowledge after attending a teaching programme (Costello et al., 2007; Mohr et al., 2002). Other research studies have indicated positive feedback from staff taught how to use PBS and improved attitudes and attributions towards people with ID

(Rose et al., 2013). However, these improvements may not be maintained over time due to factors such as repeated exposure to violence and aggression, which may increase their care burden and evoke negative emotional reactions as highlighted in this review. The current findings are consistent with other research conducted with direct care staff which found a positive correlation between negative emotions experienced by staff and severity and frequency of clients' aggressive behaviours as well as predicting use of coercive measures to manage these behaviours (Hensel et al., 2014; Knotter et al., 2013).

It is interesting that many of the HCP participants in these qualitative studies talked about their negative experiences and few recounted positive working experiences. Few HCPs could recall how they have made a positive impact on their clients. HCPs indicate experiencing negative emotions and stress that affected their therapeutic relationships. They may not have had appropriate coping resources in their workplaces or received sufficient support from their managers which may have exacerbated their stress, leaving them to feel burnt out and unappreciated. A growing body of literature suggests that this is common among HCPs working in MH services where they experience high levels of stress and burnout that can negatively affect staff motivation and staff turnover (Langdon et al., 2007; Søndenaa et al., 2015). Frequent exposure to aggressive behaviours in people with ID has also been found to contribute towards the emotional difficulties in HCPs and affect their working experience with this client population (Hensel et al., 2014).

In the main theme *Relational Interaction,* HCPs reported feelings of pride and enjoyment in their work despite the challenges of working with people with ID. They understood the importance of building rapport with people with ID as a way to ameliorate the difficulties in communicating with people with ID. Having a trusting therapeutic relationship (Ramsden et

al., 2015) is essential and can only be acquired by working competently with this population over a period of time. The therapeutic relationship is important for people with ID as many of them identified being able to build such relationships as a desirable quality that HCPs should possess and they only feel comfortable sharing about their emotional difficulties after a genuine working relationship has been established (Lewis et al., 2016; Weiss & Lunsky, 2009). Hence, training should not only focus on acquiring knowledge of ID and MH in HCPs but also on enhancing their communication and therapeutic skills.

Research indicates that more support is required to address the mental and emotional well-being of HCPs especially for those working with people with ID and MH problems (Edwards & Burnard, 2003). Although HCPs expressed a need for more resources to manage their emotions, such as having a designated MH professional, there were mixed views and reservations towards engaging with these services at their place of work. Some preferred not to deal with their emotions or were wary of disclosing their emotional reactions when at work. Help-seeking behaviours among HCPs are likely to be influenced by their work culture and environment (Chan & Huak, 2004) where there may be a lack of motivation to use appropriate resources for fear of being penalised. Alternative approaches could include introducing supervision programme and/or stress management interventions for staff. Literature suggests that having an experienced supervisor can help junior staff to cope with work stress and demands (Acker, 2011). Stress management interventions for support staff have been shown to reduce levels of distress and may improve well-being (McConachie et al., 2014). Discussions with management to address concerns and propose possible solutions to reduce the stress levels and burnout may also mitigate negative emotions and improve job satisfaction for staff (Innstrand et al., 2004).

Most HCPs working with adults with ID and MH problems do not work alone and often work in a multi-disciplinary team comprising of other HCPs. The organisational climate can have an impact on the delivery of MH services among HCPs and their psychological well-being (Rose et al., 2006). Davis et al. (2008) proposed that HCPs use a multi-disciplinary approach in carrying out MH assessment whereby a richer amount of data is collected and synthesised from different points of view in order to develop a treatment plan. This multi-disciplinary approach can also reduce duplication of services for people with ID and address the fragmentation of services, hence increasing better co-ordination and communication between different service providers. Additional benefits of this approach can include fostering social relationships and collegiality among different HCPs, providing additional cross-disciplinary training to improve clinical practice which can increase staff motivation and morale (Davis et al., 2008). Having a group of different HCPs working together with a clear shared vision may provide mutual support to carry out a consistent management plan to address the MH problems in adults with ID.

There is no clear consensus from the papers reviewed here among HCPs regarding the need for specialised MH services for people with ID. Most HCPs expressed concerns regarding manpower resources and a lack of confidence in working with people with ID in mainstream settings. They were keen on a specialist MH service to serve the specific MH needs of people with ID. However, some HCPs expressed concerns that this could be viewed as a way of depriving them of the right to access mainstream services and may discourage them from accessing services. They advocate instead for more resources to adapt mainstream services to become accessible and responsive to the needs of people with ID. Modifications in service delivery such as allowing MHCPs more time when working with people with ID and MH problems and more training and supervision by SHCPs can increase their level of

confidence in providing a service to this client group. Another option is for the specialised MH services to be embedded within community settings or co-located in primary healthcare services to increase the rates of early detection of MH problems in people with ID and improved access to services and treatments which can reduce the complexity of their MH problems (Ervin et al., 2014; Hemmings et al., 2014). In this way, HCPs can provide more resources to address the needs of FCs and advocate for their involvement in treatment plans, hence reducing the barriers of accessibility for people in ID seeking MH services. Further research should explore the views of FCs and adults with ID regarding specialist services to inform future commissioning.

Strengths and limitations of the research reviewed

The studies included in this systematic review have adequate number of participants in their samples and are comprised of diverse HCPs working in a range of settings. The review explored a variety of issues regarding the provision of MH services for people with ID, thus providing a broad understanding of the experiences and challenges that HCPs face when working with this population. In addition, it utilised a systematic approach to select and critically appraise the studies, using a structured quality assessment checklist to indicate the strengths and weaknesses of each of the studies. While the majority of the studies collected data using semi-structured individual interviews, some studies organised focus groups for data collection, a setting which can help participants to feel more at ease and share their experiences with each other. Capri and Buckle (2015) and Storey et al. (2012) chose to use a free association narrative interview where the researchers asked the participants an open-ended question and allowed them to elaborate their responses, hence giving them more control during the interview process and possibly providing richer data about their experiences.

All the studies provided information on triangulation of the results with different sources. The themes in the studies were well-supported with appropriate quotes and there were member checks to ensure its credibility. There was also rich information on the background of the research and the research hypotheses. Information on the rationale for the use of various methodologies were well-detailed. This suggests that the findings have external validity and generalizability at least within a western context.

However, there are some limitations of this review that must be noted. There is a lack of cultural diversity as the majority of the studies were conducted in western countries, hence it is impossible to generalise the results to professionals working in non-western countries. The terms *"intellectual disability*", *"mental health problems"* or *"dual diagnoses*" were used by the researchers in the studies, however, there were no clear details regarding how they defined and labelled the MH problems of adults with ID. Hence, the participants in these studies may have worked with adults with ID with a variety of MH problems. Some studies chose to label adults with ID with specific psychiatric diagnoses, such as schizophrenia and personality disorders, while others preferred not to use psychiatric diagnoses and described the MH problems as emotional and behavioural difficulties. Future research can improve the clarity with which the MH problems are described and future reviews can explore experiences of HCPs and support staff working with adults with ID who have specific MH problems such as depression or anxiety.

The selected studies lacked details to demonstrate evidence of reflectivity and description of audit trails as was highlighted in the quality appraisal. For example, the HCPs participants may have professional collegial relationships with the researchers which could influence the analysis and interpretation of the results. Some of the studies lacked details on the external

audit process, for example the themes were not validated with the HCP participants to ensure dependability. The researchers in these studies did not take into account how their views and beliefs could affect the data collection and analysis process which may suggest that the results lack objectivity. Further research can improve on these studies by describing in details how researchers' biases were addressed and actions taken to ensure the validity of the findings of qualitative research.

The findings from the meta-synthesis came from different participant groups with different levels of work experience in different work environments. The findings thus illustrate the common experiences, emotional reactions and challenges faced when working with people with ID and any nuance differences between the participant groups have not been considered. The services that the different participant groups provide may not be applicable in a non-western setting like Singapore, hence it remains unknown whether the healthcare professionals in Singapore would encounter similar experiences as those identified by the meta-synthesis.

This review lacks a quantitative element to understand the attitudes of HCPs working with people with ID and MH problems. However when the results of this review are considered alongside the findings from the Chapter 2, they can provide a holistic view of this research area to date.

Conclusions

This review highlights the difficulties that HCPs experience when providing MH services for adults with ID. Themes include identifying and understanding the complexity of MH

problems in adults with ID, factors that can affect the therapeutic relationship and interactions when working with adults with ID and the support that HCPs receive in their workplace. HCPs highlighted the negative emotions they experience when dealing with the challenges they encountered. Moreover, they described the lack of support received in their place of work to address high work demands and stress levels. HCPs acknowledged the need for more experience and additional training to improve their confidence and competency to work with this client group. Specialist MH services were proposed to address the specific MH needs of people with ID but HCPs also spoke of investing in more resources to increase accessibility of mainstream MH services for people with ID.

Summary of findings from both literature reviews

Both literature reviews summarise our understanding of HCPs' attitudes and perception towards people with ID and MH problems. Most HCPs, specifically MHCPs, lack specialised knowledge and training to work with this population due to the complexity of MH problems. The findings from the qualitative review indicate that HCPs encounter difficulties in identifying and treating the MH problems due to communication deficits, lack of resources and time. Psychotropic medication is often used to deal with the MH and challenging behaviours in people with ID as a result of poor organisational resources and deficits in knowledge regarding non-pharmacological interventions. HCPs experience difficulties understanding the MH needs of people with ID, suffer high levels of stress and have to cope with high care demands that affect their emotions negatively. Negative feelings and emotional reactions are explored in more depth in the qualitative review where HCPs cite a lack of organisational support to help them address and manage their feelings when they encounter distressing work experiences, including being a victim of violence. This leaves them feeling helpless, vulnerable and decreases their work satisfaction. HCPs in both

reviews agree that the establishment of specialised ID service may be better suited to meet the specific MH needs of people with ID and the need for additional training to increase competency and knowledge is highlighted.

The next part comprises of five studies to understand experiences of different stakeholders in a MH service for people with ID.

PART II: Empirical Studies

Chapter 4: Study 1 – Exploring the experiences of mainstream mental health professionals working with people with intellectual disabilities and mental health problems

Introduction

HCPs are often the first line of contact when the person with ID transits from adolescence to adulthood and they play a significant role in addressing the MH problems that they may experience during this period of transition (Kaehne, 2011; Young-Southward et al., 2017). However, there are some indications that HCPs are unwilling or reluctant to work and treat this specific group (McConkey & Truesdale, 2000; Ouellette-Kuntz et al., 2003).

Some of the studies involving MHPs (Longo & Scior, 2004; Marwood et al., 2018; Mesa & Tsakanikos, 2014; Rose et al., 2012; Rose et al., 2007) grouped mainstream and specialist MHPs together as a homogenous group, without considering that their work experiences and levels of training may differ. In some instances, it is unclear whether they worked in mainstream or specialist services which makes it difficult to identify any differences in the experiences and attitudes between these two groups. Research that focused on examining whether mainstream or specialist MH services are most suitable for people with ID used treatment outcomes such as length of hospitalisation stay and reduction of symptoms but did not consider other factors that may affect service provision, for example the work experiences and level of competency of service providers. As such, there is a lack of research that focuses specifically on the experiences of MMHPs to increase our understanding of how they view their work and attitudes towards people with ID.

Additionally, there is a dearth of research studies and empirical evidence regarding the perspectives and experiences of MHPs in Singapore towards this population. For example, there is a lack of understanding of the factors that contribute towards good recovery outcomes for people with ID and MH problems. MHPs in Singapore acknowledge that the current mainstream MH services have been inadequate to meet the needs of this specific population (Wei et al., 2012). However people with ID continue to access mainstream services as a first point-of-contact for MH treatment before being referred to the specialist MH ID services. Therefore, it is important to explore the perspectives of MMHPs and understand more about their experiences to find out how these professionals may impact on service provision.

The use of qualitative research enables generation of knowledge about human experiences and allows an initial exploration of the issues that affect the MHPs in Singapore (Sandelowski, 2004). A qualitative methodology applied in health-related research can produce a personal and cultural account of human experiences as well as how participants construct meaning from their experiences and provides the groundwork for future quantitative studies. Participants (i.e. MMHPs) in this qualitative research can explore issues relating to their relationship towards a specific phenomenon (i.e. providing services and care to people with ID) freely without constraints and are allowed to express how they feel and think about the MH services for people with ID in Singapore. Therefore, this study seeks to adopt a qualitative approach to explore the experiences and perspectives of MMHPs in Singapore towards people with ID and MH and/or behavioural problems.

Method

Setting

The research was conducted in a tertiary hospital in Singapore. This hospital was chosen because it is the only hospital in Singapore that offers mainstream and specialist MH services to people with ID and also provides dedicated tertiary MH treatment to the general population. A significant proportion of adults with ID access the mainstream services in this hospital and the community before they are referred to the specialist MH ID service. A clinical supervisor was situated in the hospital to facilitate the recruitment process.

Eight (four men and four women) MMHPs aged 29 to 50 years (median age 36) were recruited. All participants worked in the mainstream MH services and had no experience of working in the specialist ID service. Their years of work experience ranged from 4 to 20 years (median 9.5 years). All the participants had encountered people with ID in their line of work and provided basic treatment before referring them to specialist MH ID service. Regarding experience of working with people with ID, five of the participants had less than one year, two participants had only one year and one had four years of experience. However, this participant had little exposure to providing interventions to people with ID and was mainly involved in screening and assessment to ascertain the level of cognitive impairment in people with ID. Participant 1, 2, 3 and 8 had prior exposure working with people with ID as part of their psychiatric residency training. Four participants were medical staff (two psychiatrists and two medical officers), three were clinical psychologists and one was a medical social worker.

Participants were de-identified and be referred to by the acronym MMHP (Mainstream Mental Healthcare Professional) with the corresponding numbers allocated in Table 4.1.

Table 4.1: Demographics of Mainstream Mental Health Professionals

Participant (MMHP)	Profession	Age range	Gender	Range of years of work experience	Past work experience with people with ID
1	Psychiatrist	30-40	F	>10	<1
2	Medical Officer	20-30	M	1-5	<1
3	Medical Officer	30-40	M	1-5	<1
4	Psychologist	30-40	F	5-10	>1
5	Psychologist	30-40	M	5-10	<5
6	Medical Social Worker	40-50	F	>10	<1
7	Psychologist	30-40	F	1-5	<1
8	Psychiatrist	30-40	M	5-10	>1

Interview Schedule

Table 4.2 shows examples of the open-ended semi-structured questions that were used for the interview which allowed the participants to express their views and share their experiences freely with prompts provided. The questions addressed the issues and challenges that the participants faced working with people with ID, their views about the MH services for this population and public reaction towards people with ID and MH problems in the community. Participants were also asked to talk about their experiences of encountering people with ID in their work and their emotional reactions. They were further

asked about ways to improve the MH services for this population. The questions in the interview schedule were based on the findings of the literature reviews (Chapters 2 and 3) and discussion with academic supervisors. The academic supervisors had experience in disability-related studies and were able to provide suggestions on the topics to cover during the interview. The clinical supervisor was consulted about the interviews as she had prior clinical experiences working with people with ID in Singapore and was able to provide additional suggestions which ensured content validity. The schedule was piloted and discussed with an external MHP not related to the study to ensure that the questions were well-understood before the start of the data collection. More information of the interview schedule can be found in Appendix 2

Table 4.2: Interview Schedule

Example of questions
1. What is it like working with people with ID?
2. What makes someone suitable to work with this people with ID?
3. How do you think mainstream healthcare workers/professional staff react when working with individuals with ID?
4. When you are working with people with ID, who do you mostly work with/talk to?
5. Do you think there is a difference in how people with ID are being cared for by professional staffs and family members?
6. Are there any differences in how you manage the mental health problems of people with and without ID?
7. What do you think about involving individuals with ID having a say about how they wish to manage their health?

8. What do you think about giving individuals with ID a say in their own care management?

9. What do the people and family members find helpful when engaging with your services?

10. What could help you do to improve your clinical practice?

11. How can healthcare professionals improve the quality of life of individuals with ID?

Ethics

This phase of the study is part of a five-part study which was granted by University of Birmingham. Ethical approval was sought and approved by the University of Birmingham and the hospital ethics committee (Appendices 24 and 25). Participants were recruited and provided written consent before the start of the interviews. Audio recording was used during the interview and the recordings were destroyed after transcription of the data. The names of the participants in the written transcripts were deidentified and identifying details removed before analysis. The transcripts were stored in a password protected laptop which could only be accessed by the researcher.

Procedure

Following ethical approval, potential participants were identified by the clinical supervisor and invitation letters (Appendix 8) were distributed to them. The letter contained brief information about the aims of the study and contact details of the researcher and clinical supervisor. Potential participants who were interested in the study contacted either the clinical supervisor or the researcher to arrange a face-to-face interview. Before the start of

the interview, participants were provided with the information sheet and consent forms (Appendix 1) that contained more information about the study and their rights as a participant in the study. Participants were asked about their demographic information before the interview (Appendix 3). Each individual interview was conducted and lasted 40-50 minutes after written consent was obtained. Participants were provided a shopping voucher after the interview as a gesture of appreciation for participating in the study.

Using Thematic Analysis (TA)[1]

The interviews were audio recorded using a digital Dictaphone and transcribed verbatim. The data were analysed using TA (Braun & Clarke, 2006). TA was chosen because it offers a flexible approach for analysing data without subscribing to any theoretical or epistemological position. As there is little understanding of the current research topic in Singapore, TA offers a constructivist approach to allow the data to be analysed and reported without using any previous theoretical knowledge or understanding. This allows the researcher to take a structured approach to exploring various perspectives of the participants and summarising the key features of the data (Braun & Clarke, 2006; King, 2004).

An inductive, bottom-up approach was used to extract themes from the transcripts according to the stages described by Braun and Clarke (2006) which were summarised in Table 4.3. The initial stage of the analysis was for the researcher to familiarise himself with the data by reading it multiple times, noting down initial ideas and observations. During this stage, the researcher recorded his thoughts and ideas about the transcript in a notebook to ensure that they were not overshadowed by his own personal biases and perceptions. The

[1] Thematic Analysis is a qualitative method to identify and analyse similar or different patterns or themes within data. It is a useful tool for summarising, organising and reporting large sets of data as it helps the researcher to search for repeated patterns or themes across the transcripts.

comments were written along the right-hand column of the transcript when the participants talked about specific issues and key points. This detailed set of notes and comments guided the development of initial codes written in the left-hand column of the transcript which were assigned a number code. These codes consisted of short statements or phrases that captured the main essence of specific parts of the transcripts. The data extracts or the participants' codes were highlighted to represent the corresponding codes. After which, the codes written in the left-hand column were grouped together into potential themes, for example by identifying patterns or connections across the codes. This was done by printing all the themes so that each theme was on a separate strip of paper. After that, they were placed on the table and the themes that represented similar ideas, concepts or issues were categorised together under the master themes. Some of the individual themes were placed to one side because they were standalone, without any meaningful connections. This process was repeated across all of the transcripts. Relevant quotes from the raw data were extracted and presented against the master themes to ensure that the themes represented and captured the meaning of the raw data. Following this, the master theme and corresponding emergent themes were typed into a separate Word document with the corresponding raw data extracts. This process was repeated for the remaining transcripts.

At the final stage of analysis, a Word document that included the master and emerging themes of all the transcripts was used in which a separate colour was assigned to individual transcript to identity the different participants. Similar process was then carried out whereby the researcher printed the master themes and cut them into individual strips for a more detailed analysis. The researcher adopted a flexible stance to look for similar connections or patterns across different participants. This allowed him to reorganise and rename the master and emergent themes. Those individual themes that were not grouped

into the master themes in each transcript were also taken into consideration and grouped. After this process, the researcher compiled a table of main themes and sub-themes and the quotes that illustrated the corresponding sub-theme. More information on the data analysis process and participants' quotes can be found in Appendices 4 and 5.

The researcher is a qualified MHP who had previous work experience with people with ID and worked in a similar setting as the participants. This helps the researcher to understand the issues and challenges they faced working with this population. In addition, the researcher is not affiliated with the research site and this provides a safe space for the participants to share about their challenges without fearing any repercussions.

Table 4.3: Description of Thematic Analysis (Braun & Clarke, 2006)

Step		**Description**
1	Immersing yourself in the data	Understand the data by multiple re-readings, write down initial comments, notes or ideas
2	Developing initial codes	Generate or code interesting features of sub-themes across the transcript based on the comments or notes. Note down the quotes that are relevant to the sub-themes
3	Merging the codes to form themes	Merge the sub-themes together by collating them together. Search for common patterns of sub-themes to form a theme
4	Reviewing the themes	Check to make sure that the newly formed themes are grounded in the data. Develop a thematic map of the main themes with its sub-themes or codes
5	Defining and naming the themes	Generate names to define and describe the themes which tells the story of the data.
6	Repeat the process	The process is repeated with the remaining transcripts. Ongoing process to review and re-define the themes if necessary

7	Searching for repeated themes across the transcripts	Search for repeated or common themes across the different transcripts after individual analysis of the transcripts are completed. Re-organise and group the repeated themes, summarise the key features of the themes and extract appropriate quotes that describes the themes for report writing of the analysis.

Trustworthiness in analysis

The concept of trustworthiness is introduced in qualitative research to ensure that the findings remain grounded in the collected data (Nowell et al., 2017). The five studies described in Chapter 4 to 8 relied on the Lincoln and Guba (1986) framework of trustworthiness that encompasses four goals which are truth value (credibility), applicability (transferability), consistency (dependability) and neutrality (confirmability).

One approach to ensure credibility of the findings is the use of appropriate sample size which can determine thematic saturation. Ando et al. (2014) did not recommend a specific sample size but state that having 12 interviews provided 92% of the themes while Braun and Clarke (2013) propose a sample size of 6 to 10 for a small scaled project. Boddy (2016) recommend that the sample size is determined by the research paradigm and a larger sample size is required for qualitative research oriented towards positivism. As such, the inductive approach and interpretivist paradigm allows for the sample size to remain small. Additionally, Ando et al. (2014) suggest to focus on the depth and quality of the interviews for higher order analysis rather than the number of participants. Therefore, the number of participants (n=8) was deemed adequate for this small-scaled research study.

The process of triangulation helped to ensure that the research study was conducted rigorously and the results were consistent. Each stage of the data analysis was audited by

the academic supervisors experienced in qualitative research methodology. Two transcripts were given to them to check for consistency in coding and ensure that the issues were adequately covered. The researcher produced a summary of each interview with the emergent themes to discuss possible interpretations with academic supervisors, for example discussing and verifying the second and third stages of the analysis. The table of main themes was also discussed and verified with the clinical supervisor to ensure a good level of agreement.

Triangulation of sources were also carried out to ensure that the findings remained credible and consistent. Different perspective of homogenous sample group of MHPs, FCs and SUs were obtained in other chapters (Chapter 5 to 8) to provide multi-perspectives of exploring the MH services for people with ID in Singapore. Observations recorded during the interviews such as the participants' non-verbal behavioural cues, their tone of voice (for example pauses) and language used when describing their experiences were used to verify the themes and aid in the interpretation of the meaning.

Transparency of a qualitative study is important to ensure that findings are transferrable to other groups of participants working in a similar work environment. Clear and detailed descriptions of the research process were described in the method section, for example the details of the demographic profile and the recruitment procedures. The development of the interview schedule and data collection were clearly described and these processes were audited by the academic and clinical supervisors. The results and discussion sections were discussed with the supervisors and supported by quotes and supplement quotes in the appendices.

A reflexive journal was used to bracket the researchers' assumptions, thoughts and perspectives to ensure the neutrality of the findings. The journal was also used to note down the thoughts and reflections of the researcher during the data collection and analysis process, for example describing the difficulties encountered when conducting the research, including difficulties with recruitment. Parts of the reflexive journal are described in the Appendix 26. Additional notes including the researcher's reflections of the participants and the interview process were recorded to help him remain sensitive to the cultural context. One example is that the MMHPs were observed to be less forthcoming to discuss about the organisational support they received in their work. There were moments during the interviews where the MMHPs expressed feelings of helplessness for not being able to significantly improve the lives of people with ID. These observations were recorded in the reflexive journal to have a more in-depth understanding of their experiences and challenges they faced in working with people with ID. The process of building rapport with the participants was easier due to similar professional background and experience, therefore they were forthcoming to share in-depth and openly about their experiences.

Results

Four main themes emerged with corresponding sub-themes from the analysis. Table 4.4 shows the list of the main themes and sub-themes as well as the number of MMHPs that endorsed the themes. Quotes were chosen and italicised to describe the themes in more detail.

Table 4.4: Main themes, sub-themes and the participants that contributed to each sub-theme

Main themes	Sub themes	Participants contributing to the themes
1. Working with people with ID	i. Comparison with general population	1, 2, 3, 4, 5, 7, 8
	ii. Emotional reactions when providing services	1, 2, 3, 4, 7
2. Perception of people with ID	i. Level of autonomy	1, 2, 3, 4, 5, 8
	ii. Reaction from the public	1, 2, 3, 5, 6, 8
3. Ideal characteristics of healthcare professionals		1, 2, 3, 4, 6, 7, 8
4. Service recommendations	i. Having more resources and time	1, 2, 3, 6, 7, 8
	ii. Training community support staff	2, 3, 4, 5, 7
	iii. Empowering FCs	2, 3, 4, 5, 6, 7, 8

Main theme 1: Working with people with ID

This theme describes the comparisons MMHPs make between their other patients and those with ID. It also describes how they view the MH problems of people with ID and their emotional reactions towards this population.

Sub theme 1: Comparison with general population

The majority of the MMHPs described the challenges in understanding and communicating with people with ID and how this population were often unable to share their feelings and thoughts,

> *"They can't communicate, so when they don't feel comfortable or they feel distressed, they are not able to tell us why they are feeling like that." – MMHP 1*

> *"They have more conduct disorders, probably the borderline or the mild ones because their activity of daily living is not impaired, but they have difficulties in communicating, they have a very low frustration tolerance. A lot people in the borderline and mild groups have anger management issues, so they do not know how to handle their anger very well." – MMHP 2*

MMHPs often had to address the MH or behavioural problems themselves because they *"do not have the luxury of having these professionals (with ID specialities) around" (MMHP 1).* This was because FCs refused to be referred to the specialist services due to long travelling distance to the hospital.

MMHPs noted a higher prevalence of MH problems such as mood disorder and psychosis in people with ID than the general population and finding it more difficult to identify triggers that contribute to or maintain these symptoms which required more time to observe or check with family members to obtain a detailed history,

> *"Psychosis or even mood symptoms seem to be more prevalent among people with ID than the general population but it's more difficult, in my experience, to elicit exactly what's going on and you have to kind of roll it out and we need to observe them on the wards and to really diagnose whether they have something like psychosis over there. It involves more*

history gathering not only from the patient but also from the family." – MMHP 3

"We guess what is going on and have to have multiple hypotheses of how we can support this behaviour, or what is causing this behaviour; can we remove the stimulus that is causing this behaviour. A lot of times it's really trial and error." – MMHP 7

Medical MHPs acknowledged the limited efficacy of medication to treat the MH problems and were keen for *"more possibilities for more allied health professionals to be involved in different ways" (MMHP 3).* Psychologists shared the view that it was difficult to engage these clients in talking therapies, difficulty in *"following up"* with treatment and *"seeing through tasks given" (MMHP 4),*

"Most of them find it difficult to grasp concepts of psychotherapy, so when you talk about suitability for therapy, most of them would struggle to meet some of the criteria because they may not be able to understand some of the concepts when you try to explain to them."– MMHP 5

Sub theme 2: Emotional reactions when providing services

MMHP 2 recounted his experiences of almost being assaulted by people with ID, *"They tried to…I mean three times they failed. One tried to kick me, the other tried to poke my eyes and the other one spitted at me. Another one managed to scratch me."* He further shared about feeling intimidated and unsure how to react when he entered the hospital dormitory to meet the people with ID,

"There's about twenty to thirty patients inside the dormitory, they will surround you, especially those hyperactive patients. They will surround you and keep asking a lot of questions." – MMHP 2

Other MMHPs acknowledged that their colleagues had negative reactions of fear and uncertainty when people with ID displayed aggressive behaviours and lacked support or knowledge on how to manage them,

"I believe in a busy setting and sometimes if they are violent, it can be quite scary as well for them. Yeah for the doctors and nurses also or anyone who has not much experience dealing with this group of people." – MMHP 1

"Wary, careful, cautious, like they may think like what is unpredictable and sometimes, it's...even for with experienced ones may find themselves unable to deal…unpredictable triggers." – MMHP 4

MMHPs shared third person account of how other MHPs' lack of experience and knowledge contributed to the negative feelings and lack of willingness to care for this population, especially when they failed to detect the underlying MH symptoms and attributed the behavioural problems as a negative characteristic of the person,

"He (the person with ID) is also an elderly but because of his behavioural issue, the psycho-geriatrician is not accepting the patient also." - MMHP 1

"If they have no experience, it will be quite tough. I think they will feel overwhelmed and they may assume that it could just be a behavioural problem or this is just how they are, think to themselves that I cannot manage, I don't want to take care of them whereas they could be experiencing something like mental health issues."– MMHP 3

"So those people without the professional knowledge, they might feel scared; they might feel worried; they might feel confused; they might feel unsafe when they are working with this group of people." – MMHP 7

MMHPs reported frustration with a lack of improvement in people with ID, citing that it was *"very easy to give up on, especially things are not going well" (MMHP 4)* for them,

"Whereas if they have the right amount of support, community involvement, if their family support them even more, they could be in the community. So overall, when I see that, sometimes I feel frustrated working with them." – MMHP 3

At times, MMHPs acknowledged feeling burnt out and the work being *"emotionally draining"* when the MH problems keep reappearing or people with ID have repeated inpatient hospital admissions, *"when you are frustrated and it didn't work out, and it happens again and again and again, then whatever resources that you have from the right from the start would just.. deplete" (MMHP 4).* Indeed, MMHP 4 continued to describe how other MMHPs may become demoralised or experience burnout as an emotional response to a negative situation, for example witnessing other MHPs using restraints to address challenging behaviours,

"When you restrain and it's seems like a very effective thing...you quiet the person down and let the person not affect other people...and it's like an easy way out... just strap and then that's it... you don't have to do anything else… I would for this kind of scenario, the healthcare worker would probably feel burnout at the end of both physically and mentally because it doesn't seem to be any other way to help other than this."

Main theme 2: Perception towards people with ID

This theme primarily focuses on how MMHPs perceive people with ID with MH problems and how they think people with ID are viewed by the public.

Sub-theme 1: Level of autonomy

This sub-theme discussed how MMHPs viewed the level of autonomy for people with ID to make choices related to their lives and health. They expressed a willingness to allow people

with ID to make decisions and respect their choices, dependent on the severity of the ID and their capacity to make decisions,

> *"Everyone should have this stake and say and control in how they want to manage their health and their treatment. So again this should be the same for patients with ID. Of course, the level of participation depends on their level of disability." – MMHP 8*

Unfortunately, their 'voice' or wishes regarding their treatment or care plans were not always taken into consideration and MMHPs acknowledged that people with ID often remain hospitalised for long periods, which prevented them from engaging in meaningful activities outside in the community,

> *"It's easy to assume that they don't have needs...or whatever their needs, it's some other people's wants take precedence…" – MMHP 4*

> *"I feel like sometimes their flourishing has been stunted or their ability to… their freedom has been limited because they are institutionalized and those are more for the long stay." – MMHP 3*

Medical MHPs acknowledged the struggles in respecting and carrying out the wishes of the person with ID which may differ from their FCs, especially when FCs insisted on admitting the person for treatment against the person's wishes,

> *"In Singapore setting, we tend to listen to the family members more. That's my personal view because I work in the emergency room. Ultimately the decision to discharge or admit the patient is based on the history from family members. So if they say that they are dangerous... majority of the time we listen to the family members and the family has the final say on whether to admit or discharge." – MMHP 2*

> *"If the patient has the capacity, he knows what he wants and all that, I think we have to really tell the family members that the patient has these*

rights to decide what they want. Sometimes, it can be very difficult, for example maybe family members want to admit the patient. Then the patient refused admission. That can be really difficult for us." – MMHP 1

A psychologist MMHP noted that it was impossible to advocate for the needs of the person with ID because ultimately, they *"are not the one paying the bills" (MMHP 5).* MMHP 5 stated that people with ID lacked the ability to care for themselves and discussed the challenges in helping the person with ID to fulfil their wishes and desires as well as handling the conflicting perspectives from other stakeholders, such as the family and support staff, who often denied the person from achieving their goals,

"The thing is that we need to recognise what the nursing homes and parents are not wrong, usually the typical argument is that if the patient is not able to take care of himself, how is he going to take care another person? Right? So usually, the problem is that if he marries another girl, then he ends up having to take care of two. Yeah, so it's not that he marries and he takes care...it doesn't work that way, so unless the hospital is willing to take care which is definitely not in our ability to do so, we have to respect the family who is actually the one taking care of the patient. So in this case, yeah...likely the goals and the likes or the wishes of the patient would be overruled."

Sub-theme 2: Reaction from the public

In this sub-theme MMHPs shared their views regarding the public reaction towards people with ID with co-morbid MH problems. MMHPs explained that the public may not understand the manifestation of the behaviours in people with ID and/or ASD,

"They find it very hard to understand them or maybe just autism... I mean like repetitive behaviours and asking the same questions again can sometimes put people off if they don't understand." – MMHP 6

MMHPs noted that the behaviours in people with ID were often noticed by the public especially when their behaviours were outside the norm,

"Usually when the public encounters a person with ID just going about, they may be helpful or they may not pay much attention. It's different when a person with ID is behaving slightly differently from the rest, maybe talking loudly or suddenly shouting kind of thing, in those cases, I suppose the public might react and that is something we sometimes see."– MMHP 8

These negative perceptions of people with ID were sometimes reinforced by their family members or carers where they *"would just attribute it to, almost like blaming, the condition itself and all that" (MMHP 8).*

While MMHPs acknowledged that people with ID and MH problems were being stigmatised and discriminated against especially in terms of employment opportunities, *"Getting jobs and things like that...that can be quite difficult, I think it depends on how the employers see them. Some employers are very understanding, they accept them, some are not so accepting, can be quite difficult" (MMHP 1),* they reported that efforts had been made to reduce the stigma,

"…the government has been working quite hard to reduce the stigma" and "…services like Bzlink (community agency) who are actually hiring people especially those with autism and ID which is a good thing." – MMHP 2

Main theme 3: Ideal characteristics of healthcare professionals

MMHPs identified a number of desirable characteristic traits or qualities that were required for working with people with ID and MH problems. All the MMHPs spoke of the importance of having patience when gathering information for example, past psychiatric history from family members and hospital case notes, to understand more about the person with ID instead of rushing through the process,

> *"A lot of time asking questions again and again to family members, looking through the case note for those that do not have family members but we have to spend time looking in their case notes, so that takes a lot of time, so I think patience is a core personality trait that is needed." – MMHP 2*

Other MMHPs defined patience as being able to accept the limitations in MH recovery outcomes for people with ID, knowing that recovery is a slow process with repeated setbacks and frequent hospital re-admissions. MMHPs shared that having this quality helped them to moderate their expectations to avoid feeling frustrated or discouraged when their clients' MH symptoms did not improve,

> *"Patience in that the progress may be more gradual. For example, a person who displays some problem behaviour, more likely often will come back for admission or would present again in the emergency room. So the person cannot be so discouraged by that, so patience and committing for the long haul." – MMHP 3*

MMHPs identified the ideal clinical skills that a SMHP should possess including being observant in order to identify the MH problems, having prior knowledge and understanding of the field of ID, as well as being creative in adapting clinical techniques and strategies to suit the needs of people with ID,

"You really need to find more creative means of engaging them, you want to rely on talk therapy, it's not going to really work. You have to do more activity based, you have to do more." – MMHP 5

"I also think they need to have some past training to work with ID population, how to manage patients with ID." – MMHP 1

"Most of the time it (the behaviour) is triggered but you don't know what are the triggers, so you have to be very observant and find out why are the triggering factors and sometime it is not triggered." – MMHP 2

Medical MMHPs identified the importance of collegiality, working as part of a multi-disciplinary team consisting of other SMHPs. They spoke about their limitations in their role as a doctor and valuing the professional input and involvement from other specialists to understand the person with ID better,

"You have to be part of the team because a lot of the work as a doctor is probably actually small compared to what the allied health professions have to do as they have to do some of these sessions. You would have to be able to work with more people than just the patient and talk to them." – MMHP 3

Many of MMHPs agreed that the ideal SMHP should have a *"holistic view of the person" (MMHP 7)*, not just their medical or healthcare needs, but also *"in terms of their social and quality of their relationships" (MMHP 8).* MMHP 6 stressed the need for MHPs to remind themselves that *"there's a person behind that label"* and taking into account their strengths, limitations and support network in the community,

"Asking questions about what the person like and what the person enjoy or doing those times when this person doesn't manifest any behavioural issues. How is he or she like as a person?" – MMHP 6

Main theme 4: Service recommendations

In this theme, MMHPs provided suggestions and ideas on how to improve the service provision of MH services for people with ID. MMHPs highlighted three areas to address the service gaps, which are described in the three sub-themes.

Sub-theme 1: Having more resources and time

MMHPs shared that one of the ways to improve MH services is to allocate more resources to improve their competency. Some of the professionals discussed the resources and training that they found useful. For example, MMHPs 1 and 8 recalled brief work experiences with people with ID during their psychiatry residency training, stating that training and exposure had been limited and additional skills in *"basic communication skills, and also some tips on how to manage the behavioural issues..." (MMHP 1)* would be beneficial for mainstream psychiatrists and general practitioners working in a community setting. MMHP 3 further added that learning communication skills also include learning how to communicate and work with other MHPs in a collaborative manner. The need for more training was supported by MMHP 2 who shared a desire to learn non-pharmacological therapeutic approaches but cited lack of time and available manpower to do so, *"…it's very difficult to be trained because sometimes we don't have time, we encounter a shortage of staff."* For MMHP 6 and 7, having more time for opportunities to keep abreast of appropriate and evidence-based treatments by attending courses and conferences is also important,

> *"Reading up on research to know what the standard care is or what is evidence-based; gold-standard care that has been practiced overseas in terms of caring for adults with neurodevelopmental disabilities." – MMHP 7.*

"It will be good for me to attend course or maybe even have journal sharing or conferences to attend to hear how they understand and the disorders that they have. So I think having dialogues and case conferences will create awareness will help in better understanding. – MMHP 6

Other MMHPs discussed the administrative bureaucracy of seeing people with ID in a hospital setting where there was only a limited amount of consultation time available which was insufficient to address the complexity of MH problems in people with ID and suggested alternative ways to review their progress,

"Coming from the point of view that in a packed clinic with a few minutes available; one of the results of working with patients with ID with very limited amount of time available is that they might just be able to deal with very acute issues, and not be able to comprehensively manage different facets that need to be addressed."- MMHP 8

"They need to be seen in their community and environment, no point bringing them to clinic and ask them how things are and stuff like that. It may not work that way, for that to happen then, time dedicated for that would be necessary..." – MMHP 6

Sub-theme 2: Training community support staff

MMHPs recognised the need to provide training to community staff caring for people with ID and MH problems in residential homes. Often, these support staff would send the person to the hospital and decline to take them back after they improved, *"They feel overwhelmed because of aggressive behaviour, they bring them to the hospital because they cannot manage, it could be they have negative perception of them" (MMHP 3).* This negative perception of support staff towards people with ID was also mentioned by MMHP 5 who shared that staff were not always supportive of people with ID having friendships and companionship in a residential setting, *"That behaviour is due to a need, sexual need, but if*

you ask the nursing home, usually they would say that they just want the behaviour to stop and they are not looking at having a companion for the person."

In other instances, the support staff were said to lack the necessary knowledge and skills to comply with behavioural treatment programmes which made it difficult for MMHPs to follow up and review the outcomes of behavioural treatment plans with the support staff and the person with ID,

> *"I supposed it would be true for most nursing homes staff…when they run by shifts, then the information gets...let's say you are monitoring someone at certain time, the information gets lost somewhere, treatment is inconsistent, response is inconsistent, so there's not much reliable data or information for me to work on." – MMHP 4*

MMHPs shared that ensuring that staff in residential homes were trained in the appropriate strategies to continue caring for the person can facilitate a smoother transition of care after people with ID were discharged from hospital. They acknowledged the work done by other colleagues who had been providing consultancy and training to the support staff in residential homes to help them to understand the triggers and antecedents of challenging behaviours,

> *"We first start from transition, it can be a day transition or an overnight transition, we see how they behave and slowly re-adapt them. Our allied health team like social workers and psychologists will even conduct home visits to their adult disability homes to see how they behave over there. To teach the staff in the adult disability homes on the strategies to handle them." – MMHP 2*

> *"I think the staff in the nursing home would have received training, how to manage these group of patients. I know some of our colleagues here and psychologists, e.g JM, she has been to all these nursing homes to provide*

training to the staff there on how to manage these patients if the encounter any problems." – MMHP 1

Sub-theme 3: Empowering family carers

The involvement of FCs was something that MMHPs noted when working with people with ID and MH problems. FCs may experience feelings of grief and have differing views regarding the causes of the MH problems and hence, find the knowledge and strategies provided by MMHPs useful to clarify their doubts,

"They do come with a lot of grieving e.g. what's happening and why did the person have mental illness? Have they been doing something that have caused this person with mental illness? So there's a lot of question around the explanation of the mental illness itself." - MMHP 5

"Family members need to have adequate education (knowledge) on how to take care of them because majority of the family members, they have no idea, they do not know what they want and they do not know what to do with them." – MMHP 2

MMHPs acknowledged the important role of FCs when the person with ID was admitted to the hospital for treatment, *"caregivers are important partners who can remind, who can further clarify, who can revise the strategies or the work that you have been trying to do in session" (MMHP 7).* As such, they sought to involve and engage the FCs during the early phase of the treatment process to reduce the likelihood of the person being admitted to a residential service,

"That means if you don't engage the family member, they don't know how to handle and then there's no way for them to go home, they can only go to adult disability homes." – MMHP 2

They also shared that support and resources for the FCs were required even after the person was discharged home, as the family may continue to face challenges and feelings of uncertainty in deciding whether to provide opportunities for their family member to become independent in the community,

"We have done all we could to support the family but the family still finds it difficult to bring the patient out or allow the patient to go out. Therefore, it ends up having the patient to be kept at home which is not ideal." – MMHP 8

MMHPs also recalled positive and negative experiences of working with people with ID, stating that the lack of family involvement was more common in people with severe forms of ID due to their FCs being too overwhelmed and distressed to continue taking care of them. On a positive note, MMHPs reported that the involvement and empowerment of FCs during the treatment process help to improve family relations and strengthen the relationship between the person and their family,

"In terms of more negative experiences, those with more severe forms of ID and where family has neglected them down, this becomes basically their home. Most of the time, they have disruptive behaviour and the caregivers can't manage. They don't know what to do so some of them feel overwhelmed and stressed, that's why they're referred here or seek treatment here." – MMHP 3

"The positive thing about that would be that you see the bond between the patient (person with ID) and their father, and that's one thing somehow, it's feels like that is also what matters, there's no way that he would probably get it (without the intervention)...but you can see that he's happy with that.. at least this boy is happy and seemed joyful with some things that the parents do with him…" – MMHP 4

Discussion

The study has collated narratives of the experiences of MMHPs working with people with ID and MH problems. Individual face-to-face interviews explored their perspectives of contact and work with people with ID when they encountered them in mainstream services. Moreover, MMHPs provided their views and recommendations on improving the services for people with ID. TA was used to identify four main themes: (1) Working with people with ID, (2) Perception of people with ID, (3) Ideal characteristics of healthcare professionals, and (4) Service recommendations.

MMHPs noted difficulties understanding and identifying the MH problems in people with ID as compared to the general population due to barriers of communication. Poor understanding of MH issues due to communication deficits in people with ID has been well documented in research (Bekkema et al., 2014; Pelleboer-Gunnink et al., 2017; Sowney & Barr, 2007; Storms et al., 2017), hence it is not surprising that MHPs in Singapore face this same challenge. Additionally, MHPs with a short stint of working with this population during their postgraduate training find that their level of training and work exposure is not enough for them to be equipped with adequate skills to interact with people with ID when they access mainstream MH services. Indeed, MMHPs expressed pessimistic views regarding the ability to engage with people with ID because of their cognitive and communication impairment, indicating a resistance to shift to non-pharmacological approaches to deal with MH problems. Previous research has provided evidence that MMHPs may lack the necessary skills to adapt their therapeutic techniques and resources to fit the needs of this population (Marwood et al., 2018; Shankland et al., 2015; Willner, 2005) despite overwhelming

evidence for the effectiveness of psychological therapy for people with ID (Hamers et al., 2018; Hassiotis et al., 2013; Marshall & Ferris, 2012).

MMHPs' emotional reactions reported in this study are common given that research has found that MHPs feel less positive and hold negative attitudes in response to violent episodes involving people with ID (Araten-Bergman & Werner, 2017; Campbell, 2013). However, it is not surprising that few of the MMHPs in the study shared their personal feelings and instead adopted an external or third-person stance when talking about emotions by using pronouns such as *'they'* and *'you'*. MMHPs in the study might have felt uncomfortable about sharing their personal feelings and thus chose to relate their colleagues' experiences and feelings as a way to avoid discussing their own emotional reactions. Moreover, it may also be possible that MMHPs did not have many encounters with this population and hence, may not recall much or be able to reflect on particularly stressful experiences.

The use of restraints in healthcare settings has been shown to affect HCPs (Jones & Stenfert Kroese, 2008). MMHPs in the study shared their concerns regarding the use of unsafe practices that contributed to their negative emotional reactions. The use of restrictive practices may be an indication of frustration when MHPs feel demoralised and want to give up when their clients with ID show no improvement in their challenging behaviours. A low arousal approach can be used to de-escalate behavioural problems, decreasing demands, avoiding triggers and behaviours to reduce conflicts with the person (McDonnell, 2010). This approach avoids the use of punitive consequences for people with ID and instead seeks to help them to reduce their negative feelings of stress and frustration. Hence, there is a need

for organisational support to provide clearer guidelines and train MMHPs to use restrictive practices appropriately and to explore alternative strategies to be used instead.

The high prevalence rate of MH problems among people with ID in Singapore is something that MMHPs acknowledge in this study and confirms that people of ID have a higher vulnerability towards developing MH problems (Cooper et al., 2007; Moon et al., 2020). MMHPs noted differences in working with people with ID and pointed out a lack of structured protocols and guidelines in conducting assessment and treatment to address the MH problems. Additionally, MMHPs in the study mostly adopted a bio-medical approach to focus and treat overt behavioural symptomologies and found it difficult to explore environmental or social factors that may trigger or escalate the severity of MH problems. Previous research suggests adopting a social model of disability and for MMHPs to spend more time investigating the environmental and social factors that maintain presenting MH problems rather than focusing on diagnostic labels (Hare et al., 2016).

In the second theme, MMHPs reported difficulties carrying out the wishes and desires of people with ID despite acknowledging that they have the right to express their views about their care plans and treatment options. MMHPs expressed disappointment that those with mild levels of cognitive impairment were not allowed opportunities to express their desires or needs, instead having to accommodate the needs and wishes of other stakeholders, such as FCs and support staff. Medical staff often acceded to family members' wishes and needs at the expense of the person's autonomy and freedom to decide how they want to lead their life. The current findings also highlight the predominant collectivist culture in Singapore where people identify themselves as part of a larger social identity group, as well as ascribing to the virtues of filial piety and strong beliefs of family hierarchy which

prescribe that family members are to be respected and consulted when making important life decisions (Liu, 2005). Another explanation is that MMHP participants of the current study encounter difficulties in determining who is the client. In Singapore, family members often pay on behalf of their relative with ID for the healthcare services that they receive (Lai, 2015) and as a result, HCPs may feel obliged to prioritise FCs wishes. This creates challenges for MMHPs to advocate for people with ID to express their choices and consider their wishes, as family members may reject them in favour of their own needs. MMHPs may not see the need to go against the cultural norms and needs of the FCs to allow the voices and views of people with ID to be heard and instead defer the decision-making to the SU's family.

MMHPs in the current study perceive that the public holds negative attitudes towards them, for example being unsuitable for employment. This stigmatisation of disability is common in other cultures and it has been found in the UK, Hong Kong and Libya that there is a preference for social inclusion and 'sheltered' services (Benomir et al., 2016; Coles & Scior, 2012; Sankhla & Theodore, 2015; Scior et al., 2010; Sheridan & Scior, 2013). A lack of understanding of people with ID, especially with regards to their behaviours when they are out in public may reinforce the negative stereotypes of dangerousness that may affect their employment and living opportunities (Werner, 2015). Although research indicates that negative attitudes and strong views about social segregation of people with ID in East Asian culture are common (Hampton & Xiao, 2013; Scior et al., 2010), there is a lack of peer-reviewed research specific to Singapore. However, anecdotal reports from the media indicate low employment rates for this population (Tiah, 2019) and the urgent need for employers to consider inclusive practices to hire people with disabilities (Chiu, 2019). The MMHPs in the current study remarked on the strong push by the Singapore government to

reduce prejudice and stigma through the use of community agencies to provide additional training and employment opportunities.

The issue of sexuality was brought up and MMHPs reported that support staff and FCs are not keen to explore and address appropriate ways to deal with sexuality issues. MMHPs in Singapore appear reluctant and unsure as to whether they should discuss with FCs and support staff the need for people with ID to have interpersonal and/or intimate relationships, hence unwillingly to challenge their negative attitudes. Cultural factors such as individualistic versus collectivist values may also contribute to the responses to and perceptions of sexuality issues and interpersonal relationships of people with ID (Ćwirynkało et al., 2017; Ditchman et al., 2017). People with a non-western culture are less favourable towards the sexual rights and autonomy of people with ID (Sankhla & Theodore, 2015). Research has indicated that MHPs can play an important role in normalising these concerns and help support staff to understand the rights of people with ID in expressing their sexuality appropriately (English et al., 2020).

MMHPs in this study identified desirable qualities including patience, willingness to work in a team, clinical skills and awareness to see beyond the MH problems of people with ID. They value training and supervision to improve their skills and prefer to work closely with a multidisciplinary team to identify and treat MH problems. The attribute of patience was considered to help allay burnout and soften feelings of disappointment or frustration about the poor outcomes in people with ID. Moreover, this attribute was viewed as a way for MMHPs to be more thorough and comprehensive in their assessment of people with ID although building therapeutic rapport with them was not mentioned by the participants of this study. HCP participants of another study choose to develop a core competency

framework that identifies skills of partnership, collaboration and having good communication skills as ideal attributes (Weise et al., 2017) while others value interpersonal characteristics of warmth, openness and gentleness to promote empowerment and foster genuine relationship with people with ID (Stenfert Kroese et al., 2013). MMHPs in the current study recognised the need to move beyond concentrating on MH problems and viewing their clients in a holistic manner, taking into account their strengths including their relationships and interactions with their family and community.

Having more resources for training helps to address the gaps in knowledge, challenge and ameliorate negative misconceptions in HCPs. MMHPs in this study stated that having knowledge in ID and appropriate training would increase their confidence to provide MH services for people with ID and improve the service provided by support staff. Organisational factors such as lack of time and available manpower are barriers to improving the current service provision, in which mainstream professionals have difficulties with follow-up treatment for people with ID and thus choose to refer them to specialist MH ID services. MMHPs appear to be concerned that the hospital environment is not a suitable location to review the progress of people with ID and they prefer dedicated time to review them in their own community. The development of community services to provide specialist ID services is seen as a better alternative for easier accessibility to SMHPs with specialist expertise and knowledge of ID (Hemmings et al., 2014).

Negative attitudes and perceptions of challenging behaviours of people with ID may impact on the experiences of carers and contribute towards this population staying longer than necessary in hospital (Hensel et al., 2014). MMHPs reported difficulties in discharge planning for people with ID where the residential support staff refused to take them back

because they felt unable to deal with the challenging behaviours. Involvement of MHPs such as psychologists in a community setting can provide additional training and support for residential staff to give them the necessary skills and confidence to carry out basic interventions with people in ID (Stenfert Kroese & Smith, 2018). Training staff in PBS (Allen, 2009) has been shown to have good outcomes (Dodd et al., 2013; Rose et al., 2013). Education is an important contributor to increase staff's awareness and understanding of the behaviours of people with ID and can also change their negative misconceptions of sexuality issues relevant to people with ID (Costello et al., 2007; Woodward & Halls, 2009).

MMHPs also want to involve the FCs when adults with ID are hospitalised for treatment. Often the FCs feel confused and blame themselves for not being able to take care of or manage their relatives' behaviour (Ali et al., 2012). In Singapore, the welfare of its citizens is the responsibility of the family rather than the state, where the family is expected to assume the responsibilities of providing care with minimal need to use state resources (Hwang, 2018). Hence, FCs sometimes choose to deal with the challenging behaviours or MH symptoms on their own until it becomes too overwhelming for them. By then, MMHPs note that FCs have become disempowered and not keen for their family members with ID to be discharged and return home. Early engagement with FCs can alleviate their psychological distress and address any problematic issues that they experience when caring for their family member with ID thus preventing a crisis to develop (Dawson et al., 2016). In addition, MHPs can provide signposts to community resources for them so that follow-up intervention and support can continue to address their difficulties. MHPs' experiences of involving FCs reinforces their views that in a collectivistic culture like Singapore, FCs play a vital role in ensuring continuity of care after the person is discharged (Kee, 2004).

Implications of findings

The findings of this study highlight more training is necessary for MMHPs. MMHPs are often the first point of contact for people with ID and their FCs in seeking MH services. On-going regular training is necessary for MMHPs to keep abreast of evidence-based practices in MH issues. Also, training in non-pharmacological interventions such as Cognitive Behaviour Therapy (CBT; Jahoda et al., 2017), relaxation techniques and behavioural management (Hassiotis et al., 2009) needs to be prioritised. MMHPs should be encouraged by their managers to attend these courses by allocating protected time for them as part of their professional development. Supervision by experienced and specialist clinical staff can guide MMHPs and help them attain interpersonal skills to build rapport with this population. More involvement by the SMHPs to provide community-based services for people with ID, reviewing the competency of support staff working in the community and working alongside MMHPs to support them is also recommended. More support and resources need to be targeted at FCs to ensure that they are equipped with relevant skills and techniques, can address their own mental well-being and are encouraged to liaise with community services to ensure a smooth transition from hospital. Lastly, the findings of this study suggest that increasing public awareness by means of educational campaigns to improve the public's reactions and attitudes towards people with ID and to promote their autonomy and independence would also a desirable service development.

Conclusions

This study provides a unique understanding of the perspectives of MMHPs in Singapore and their experiences of working with people with ID. The findings provide an insight into the

challenges of providing MH services to people with ID as compared to the general population. In this study, MMHPs identified gaps in their knowledge and weaknesses of mainstream MH services that are likely to have an impact on their emotional reactions and willingness to work with this population. The participants were keen for allocated time to undergo more training to increase their competency in working with this population. Recommendations for service improvement include increased training for support staff in the community, providing community-based services led by SMHPs and empowering and equipping FCs with knowledge and evidence-based techniques such as CBT and behavioural management interventions.

Chapter 5 describes a study that allows the voices of SMHPs to be heard as they share their experiences of and insights into providing a specialist MH ID service.

Chapter 5: Study 2 – Exploring the experiences of specialist mental health professionals working with people with intellectual disabilities and mental health problems

Introduction

There are differing views regarding the various service models and provision for people with ID (Davis et al., 2008; Sheehan et al., 2013). Mainstream health services have increased their accessibility towards this group in line with government polices of integrating them in the community where HCPs have reported positive attitudes working with them (Al-Zboon & Hatmal, 2016; Gill et al., 2002). However, findings are not clear cut regarding MH issues. Chaplin (2004) noted that people with ID receive a poorer standard of care and experience worse outcomes compared to the general population when accessing mainstream MH services. Adults with ID sometimes have difficulties discharging back to their communities and restrictive practices, including the overuse of psychotropic medication, are the common treatment approaches to deal with their MH symptoms (Bowring et al., 2017; Chaplin, 2011).

Some countries including the UK and Canada have established separate specialist MH ID services to address the specific needs of this group (Bailey & Cooper, 1997; Lunsky et al., 2008; Turnbull, 1995). Proponents of specialist services argue that a multi-disciplinary approach pools resources and different specialities of MHPs together, which improves the coordination of services between tertiary hospital and community setting for people with ID seeking outpatient MH services (Kwok, 2001; Sinai et al., 2013). Others have suggested that trained MHPs are better suited to meet the needs of the ID population especially those experiencing severe MH problems and work with FCs to facilitate easier discharge to the

community (Reid, 1995). Specialist MH ID services serve a higher proportion of individuals with moderate to severe symptom profile when compared to mainstream services (Lunsky et al., 2008) but are able to provide a comprehensive assessment and treatment for individuals to be successfully reintegrate into the community to continue receiving outpatient MH services (Richings et al., 2011; Xenitidis et al., 2004). In line with normalisation principles (Nirje, 1969) and to improve accessibility of MH services for people with ID, the provision of specialist MH ID services in the UK is shifting from a hospital-based institutionalised model of care to community settings, where people with ID are seen near their homes (Hemmings et al., 2014). SHCPs are collaborating with community partners and MHCPs such as general practitioners to provide additional training and expertise to support them working with people with ID (Farrington et al., 2015). It has been reported that MHCPs often stress the need for additional training and can feel overwhelmed when working with this group (Lin et al., 2009; Sajith et al., 2017; Wilkinson et al., 2012). People with ID and their FCs have noted that community MH services are more responsive to their needs, receiving more frequent consultation sessions and practical advice on how to take care of their family members (Hemmings et al., 2009).

There is emerging research that explores the views and experiences of MHPs working in specialist MH ID services. The views of learning disabilities nurses have been explored by (Doody et al., 2018). Their participants made suggestions for improving mainstream services through training and education. ID nurses found their work challenging and noted a lack of organisational support to address their emotional reactions (Capri & Buckle, 2015; Lee & Kiemle, 2015). Other research found shortage of specialist MH ID services, lack of coordination between different ID services and ID clients being excluded from mainstream services (Scior & Grierson, 2004).

Much of the literature is focused on western perspectives and very little known about MHPs working in specialist MH ID services in Asian countries. Most of the studies conducted within the Asian context are mainly quantitative and focus solely on medical staff, ignoring the views of other MHPs from different specialisations (Lin et al., 2009; Sajith et al., 2017; Wong & Wong, 2008). The voices of the support staff and FCs have been explored in Hong Kong without including the views of SMHPs (Wang et al., 2011; Wong & Wong, 2008). There is a lack of qualitative studies conducted in Singapore and other Asian countries that provides an insight into the experiences of SMHPs despite the establishment of specialist MH ID service in Hong Kong and Singapore (Kwok, 2001).

This current study addresses the research gaps and builds upon the previous study reported in Chapter 4 to explore the experiences of SMHPs. In doing so, this study aims to understand more about their roles in the specialist MH ID service and how they work with other stakeholders to meet the MH needs of adults with ID. Hence, the study aims to explore the experiences of SMHPs and to seek their views on improving the current service for adults with ID in Singapore.

Method

Setting

This study was carried out in a tertiary hospital in Singapore which offers specialist MH ID services to adults with ID.

Participants

Eight (four men and four women) SMHPs aged 25 to 38 years (median age 32) were recruited from the hospital. All participants worked in specialist MH ID service at the point of recruitment. Length of work experience ranged from 2.5 years to 15 years (median 6 years) and participants had 1 to 6 years (median 2.5 years) of work experience working with adult with ID. Only participant 6 had a professional postgraduate qualification in ID (master's degree in the field of ID and ND), the others had obtained their skills through on-the-job learning and exposure. Participant 2 and 5 attended basic training in knowledge of ID and adaptation of therapeutic skills for this group.

Participants were referred to as Specialist Mental Health Professional (SMHP) and the corresponding number allocated to them in Table 5.1 to protect their confidentiality.

Table 5.1: Demographics of Specialist Mental Health Professionals

Participant (SMHP)	Profession	Age Range	Gender	No of years of work experience	Current years of work experience with people with ID
1	Speech Therapist	30-40	F	5-10	>1
2	Nurse	30-40	M	>10	>5
3	Psychologist	20-30	F	<5	<5

4	Psychiatrist	30-40	M	5-10	>1
5	Psychologist	20-30	F	<5	<5
6	Nurse	30-40	M	>10	>5
7	Medical Social Worker	30-40	M	<5	>1
8	Occupational Therapist	20-30	F	<5	>1

Interview Schedule

The interview schedule contained the same set of semi-structured questions described in Chapter 4, Method section under the "Interview Schedule" (Page 131 and Appendix 2). The questions were validated by the academic and clinical supervisors after a few iterations and were piloted with an external MHP not related to the study.

Procedure

The same set of recruitment procedures and ethics were used as in Chapter 4, Method section (Page 132).

Analysis

The transcripts were individually analysed using TA (Braun & Clarke, 2006). The process was carried out as described in Chapter 4, Method section (Page 133). The researcher undertook the primary analysis of the transcripts, identifying and noting down ideas and observations in the right-hand column of the transcript to highlight the key points that the participants discussed. Initial codes were developed and written on the left-hand column based on the comments, observations and notes. After which, the initial codes were printed and

categorised based on similar patterns and connections to form master themes with corresponding emergent themes. This process was repeated across all of the transcripts.

The master themes and corresponding emergent themes from each transcript were extracted and complied in a Word document. The second iteration of analysis was carried out similarly to re-categorise the themes from all the transcripts. This was carried out by printing the themes on separate strips of papers and rearranging them according to similar patterns or connections found across the different transcripts. As a result, some of the master themes and emergent themes were relabelled to capture the essence of the raw data. A final table of main themes and sub-themes was compiled and quotes were chosen from the raw data to represent the themes. More information on the data analysis process and participants' quotes can be found on Appendices 6 and 7.

Credibility checks

Credibility checks were made according to the Lincoln and Guba (1986) framework of trustworthiness described in Chapter 4, Method section under the "Trustworthiness in analysis" (Page 136). The researcher had numerous discussions with his academic supervisors to discuss the interpretation of the findings and achieve consensus. The clinical supervisor was also consulted to verify the findings and a reflexive journal was used to minimise the influence of the presumptions and views of the researcher during the data analysis. It was noted that the researcher did not encounter difficulties building rapport and the participants were forthcoming in sharing the issues and challenges they face working with this population. Unlike the participants in Chapter 4, it was observed that they were more willing to discuss the level of organisational support they receive to carry out their work with people with ID.

Results

Analysis of the eight interviews indicate four main themes with sub-themes after the analysis. Table 5.2 shows the list of main themes, sub-themes of SMHPs and the number of representations in each sub-theme. The quotes were taken from participants and italicised to illustrate the themes with clarity.

Table 5.2: Main themes, sub-themes and the participants that contributed to each sub-theme

Main themes	Sub themes	Participants contributing to the themes
1. Role of specialist mental health professionals	i. My work is challenging	1, 2, 3, 4, 7, 8
	ii. Building a therapeutic relationship	1, 2, 3, 4, 5, 6, 8
	iii. Desirable staff attributes	1, 3, 4, 5, 7, 8
2. Ensuring continuity of care	i. Involving family carers during the treatment process	1, 2, 3, 4, 5, 6, 7, 8
	ii. Working with residential support staff	1, 2, 3, 4, 6, 7, 8
3. Disempowerment of service users	i. *"They should be given more choices"*	1, 2, 3, 4, 5, 6, 7
	ii. *"The public just want to get away from them"*	2, 3, 4, 5, 6, 7, 8

4. Improving clinical practice	1, 2, 3, 4, 5, 6, 7, 8

Main theme 1: Role of specialist mental health professionals

This theme describes the role and responsibilities of SMHPs working with adults with ID and MH problems. SMHPs shared how they felt and the challenges they had faced working with this group. The theme also describes the desirable attributes that SMHPs should possess to work in this service.

Sub-theme 1: My work is challenging

SMHPs identifed feeling uncertain and fearful when they first started to work in the specialised service. The majority of them did not apply to work in this field and were assigned by their managers based on manpower needs, *"I didn't have a choice, so when I came in because they have a lack of staff" (SMHP 5).* Some remembered their first time working without any prior experience or exposure and initally had felt fearful because they believed that challenging behaviours may be triggered at any time, *"The first experience can be quite daunting, can be quite erm..scary at times" (SMHP 1).* Some SCHPs admitted feeling uncertain about communicating with adults with ID and having to take time and effort to observe the person and learn skills from other SMHPs,

> *"I find it very difficult to understand their thought process, or maybe sometimes what they are trying to communicate, I don't really know…" – SMHP 3*

> *"That would be one of the main challenges because it takes time, it takes observation, and it takes a trans-disciplinary approach. So this is a big*

learning curve, because it presents opportunity when I work with my team." – SMHP 7

SMHPs identified their roles in this specialised service differently based on their professional identity. Some of them identified themselves as a caretaker or authoritative figure to their clients by providing basic step-by-step instructions, *"I feel like I'm a mother to them. I need to tell them what to do and what to take care of" (SMHP 8),* while others described their role as supporting and including the FCs during the treatment sessions to equip them with the necessary skills to understand their relative with ID better,

"I would be working with their caregivers more, understanding the issues and challenges that caregivers face in their care. Similarly empowering and journeying with them in this journey of helping them to find suitable services, addressing caregiving or parenting issues." – SMHP 7

"I instil the idea that the parents are the co-therapists, so they should be equally involved in the session together to understand and manage the behaviours." – SMHP 5

Regardless, SMHPs shared they work within a team, consulting with each other and making collaborative treatment decisions together in order to provide a high level of care,

"We all work as a team to help the patients. To help the patients to provide the best care that we can have to them. So I feel like working with this team is very cohesive, We support each other. We help each other and collaborate so that we can provide the best to the patient." – SMHP 2

Although SMHPs acknowledged working with adults with ID takes up more time and resources, such as preparing specific materials for individual clients based on their level of cognitive ability, they described enjoying their work*, "…the job it is very fulfilling, like very*

satisfactory for soul" (SMHP 5), others reported satisfaction in their work over time especially when SUs improved after treatment,

> *"That fear and daunting feeling will start to decrease as the time goes by."*
> *– SMHP 1*

> *"That client's baseline behaviour was okay and then sometime happened between...the trigger happened and after that you see them back to their baseline, so that is very fulfilling kind of experience to see..." – SMHP 5*

Sub-theme 2: Building a therapeutic relationship

When talking about the challenges faced when communicating with adults with ID, SMHPs talked about using different strategies to focus on building a therapeutic relationship or rapport in this second sub-theme. Some of the SMHPs referred to engaging the interests of their clients as a starting point in building rapport,

> *"I am engaging them with activities, like games, puzzles, colouring, drawing.., Often at times, I would ask their families and caregivers, what does this individual like? What's their interest in?" – SMHP 3*

SMHPs paced their intervention according to the level of engagement of the SU. They relied on non-verbal cues to identify any signs of distress, using *"lots of gestures and visuals without using words and full sentences" (SMHP 1)* to connect with them and check whether they wished to continue with the session,

> *"And also mood I think...sometimes they come in with better mood, or sometimes they are in the better mood, then I can do more work with them. Sometimes their mood is affected, then I can't do much..." – SMHP 5*

SMHPs relied on basic visual aids with short verbal instructions. SMHP 4 emphasised that he collaborated with other staff to develop a communication passport for people with ID to

help other staff understand them better and have some knowledge of triggers that may affect the behaviours of the SUs,

"Usually at the start, I will do a mixture of some of the behavioural interventions, we will use visual aids, we will use short and simple instructions to go through what they did to do and we will get them to follow and do tasks together. So this is more like to work with them, to enable them to follow instructions." – SMHP 8

As well as having the communication passport, SMHPs also reported developing behavioural support plans to deal with challenging behaviours. This SMHP felt that it was important to spend more time with the person and use non-verbal communication approaches to build rapport with them,

"We come up with positive behavioural support plan. This is very unique for this group…we believe that patient definitely has the function, the reason for this patient behaviour. We really think first of all, how to change the environment, to suit the patient's needs rather than fixing their problem. We are not going to have punishments for their challenging behaviours. We really support their good behaviour. We try to teach them the alternative behaviour to replace the challenging behaviour…" – SMHP 6

However, another SMHP raised concerns because he felt that spending too much time with a particular client may affect their workload and colleagues may perceive that he is not working productively and be viewed as *"lazy",*

"If I spend one whole day to do activity with one profound ID patient, I think nobody is going to praise me that much because I never do the rest of my work. I think that might be a very big challenge." – SMHP 2

Instead, this SMHP suggested spending short periods of time to do simple activities with them daily to build a therapeutic relationship with them and as a way to remind himself that it is important to spend time with the people that he is providing care and services for despite high work demands,

"Yeah I think most importantly is to do something simple. Maybe today you have a lot of things to do but you can spend a good 5 minutes with another patient which you usually don't. But these 5 minutes is possible. By doing this extra 5 minutes, it's possible. It's still within your means, so take the trouble to go for this extra mile." – SMHP 2

Sub-theme 3: Desirable staff attributes

In this third sub theme, many of the SMHPs stressed that having a passion for or interest in working with this specific group is an important prerequisite,

"You will definitely have to have a heart (laughs). Passion." – SMHP 7

Some described how their interest began during volunteer work or on placement as a healthcare student which made them want to join this specific service after their graduation,

"And through volunteering, I found myself liking to know with these individuals and just feels like I can do a bit more, so that is why I also decided to pursue it professionally as well." – SMHP 3

"I started off as a student attached to working with this group of disability, autism and ID... got me interested to work further in the other side." – SMHP 8

The importance of having passion was stressed by participants as it helped to alleviate some of the negative feelings or challenges that they encountered in their work, providing them

with motivation to continue their work with this group. They emphasized that having passion, interest and empathy trumped the need to have prior skills and knowledge,

"...because you have the interest, then you will overlook a lot of things that come with it, so you know how like initially I was telling you about the daunting feelings, then a little bit of worry and scared..." – SMHP 1

"Those who are willing to come and work with… they have compassion, they have this passion to work with disabilities... I think the most important part is to be interested to work with them, then along the way the skills can also learn later." – SMHP 8

It also became evident that passion is important when advocating for the rights of people with ID,

"…stand up for the rights and pursue for more for this population also." – SMHP 3

SMHPs also spoke of the importance of being prepared and flexible to deal with unpredictable situations and with challenging behaviours that the adult person with ID might display,

"They have to be prepared. Especially for the challenging behaviour the patients have. Because not everyone can tolerate people screaming…passing motion all over the places, shouting, scratching themselves, biting other people, eating non- edible things like diaper. Not many people can tolerate these kinds of behaviours and if they are not ready, they can be very affected." - SMHP 2

They also felt that safety issues are something that MH professionals should consider before joining this field because of their personal experiences when their safety was compromised.

Hence, being calm and composed when dealing with an unpredictable and potentially aggressive situation is a necessary quality that SMHPs agreed on,

> *"They should consider about the safety issue, whether they are comfortable to deal with population who are more likely to be unpredictable compared to the general population. I was pregnant at a time and went for community intervention, and the patient pushed me. Then, I have to call the hospital and have to see if there's any help I can get from them…"– SMHP 5*

> *"They shouldn't be affected emotionally by the people with ID and also their behaviours, because they can be potentially aggressive without any reason." – SMHP 4*

SMHPs also reflected on work culture and stated that it is important to have the skills to *"work with different people, like allied health and also the patient's family members to work together. Not only focus on the ID patient and themselves, but also work with other people together" (SMHP 4).* They viewed having patience as essential when working with this population, taking time to talk to the person, being tolerant of their challenging behaviours and not expecting significant outcomes in the short-term,

> *"Be patient in personality and a loving heart. You cannot be someone who is very rush in personality. Be gentler, more patient, more tolerant to people's behaviour. Those are very important and maybe one more would be the person should not expect to see a significant improvement within a short period of time*." *– SMHP 2*

Main theme 2: Ensuring continuity of care

This theme reflects the issues that arise when ensuring that there is continuty of care after the adult person with ID is discharged from the hospital. SMHPs raised the difficulties they

faced when engaging with different stakeholders and their experiences of helping the person to settle back into their communities.

Sub theme 1: Involving family carers during the treatment process

The level of involvement of FCs was seen as vital to the delivery of care because SMHPs acknowledged that *"…the family unit is very important in the Asian culture, most of them live with their family and unable to live independently" (SMHP 4).* The family unit was viewed as providing *"one-to-one care"* and FCs *"…will know a little bit more about the patients themselves and actually gives us a lot more insight of their family member's behaviours at home" (SMHP 1)*, hence SMHPs often worked with them during the treatment phase so that strategies were continued after discharge,

> *"I try to incorporate family carers, giving them caregiver training or what the work I have been done with their family members...so they will be able to replicate the work at home and be involved during the intervention process." – SMHP 5*

Some SMHPs seemed cautious and raised concerns that FCs may become overly protective towards their relative, such as helping them to perform daily tasks on their behalf or avoiding bringing them out in the community. They offered possible explanation that FCs may view their relative with ID as 'incompetent',

> *"Parents are usually more "helpful" because they know their child has some disabilities, so they want to do everything for them and it is easier to do that rather than training them to be independent as it saves a lot of time. Sometimes the parents do a lot for them so in the end, they lose a lot of skills." – SMHP 8*

"They (family carer) would not bring them (people with ID) out, so they would manage it by avoidance because of very bad past experience bringing them out before." – SMHP 5

Sometimes SMHPs faced resistance from FCs who were not willing to engage with them, *"…they are not very open to suggestions from healthcare professionals, so sometimes, they feel like they know their own child best. Sometimes they view our advice maybe not practical, not helpful. That's when they are very guarded and get aggressive with us" (SMHP 3).* In some instances, SMHPs seemed bewildered as to why some FCs abandoned their relative with ID in the hospital and refused to remain in contact with them. They surmised that the demands of taking care of the person and managing their behaviours had become too challenging that the FCs decided to cut all ties with the person. They further postulated that FCs gave up on their relative following repeated admissions and little improvement in their behaviours, reinforcing their belief that their relative will never become 'better' and SMHPs could do a better job in providing care for them.

"They kind of abandon their beloved ones, their child here with us for so long and you know from the beginning when we accepted your son or daughter, there was a promise from you that after a few months, you will bring them back but after that it didn't happen and they just leave it and later you became uncontactable or even disappeared. You will wonder why they are so cruel and they don't commit to what they promised. They are able to just leave or just throw the person here for so long without even seeing the patient." – SMHP 2

"Sometimes they (family carer) feel since my family member / loved one is so well taken care by the whole team in the hospital then I don't want to discharge the patient to anywhere else. So they will come up with a lot of reasons/ excuses during the discharge phase, like they can't get a maid or

a proper nursing home so they are unable to take care of the patient." – SMHP 6

Regardless of the negative experiences they encountered with FCs, SMHPs remained adamant that the important goal is for the person to be discharged back to their home with their FCs because of the relationships and bonds in the family which they consider to be protective factors for the person with ID,

"I think for family members right, they are very close to the patient, they really understand the patient's behaviour and they understand how to manage. Maybe if you give them some training, caregiver training, education to them and share the strategies to them. They are able to take care of the patient." – SMHP 6

"They are here for a period of treatment but long term wise, caregivers are those who care for them, they are the part of their lives." – SMHP 7

Despite the challenges in involving the FCs, SMHPs noted positive outcomes when the FCs did find the services useful, *"it is difficult to involve the parents, but those who are involved…I can see better prognosis" (SMHP 5).* They recounted positive experiences,

"There was a patient with a behavioural concern. He was going to hit a family member when his demand was not met. We came up with a communication whiteboard and taught him to use the communication cards to express his needs, request food, or what kind of activities he liked. We also shared the experience with the family to come up to have a communication board at their own home to help them understand his needs and to manage his behaviour. This patient was discharged home and was not readmitted. So I believe the patient was able to communicate well in the home. The family appreciated us and wrote a thank you card to us. Even the patient wrote a simple thank you to us which makes us feel very happy and feel a sense of job satisfaction." – SMHP 6

Sub-theme 2: Working with residential support staff

SMHPs hightlighted challenges when working with residential support staff, dealing with their skepticism and refusal to admit them into residential homes, fearing that they were unable to manage clients' behaviours. SMHPs felt that the residential support staff were not receptive towards learning treatment strategies and re-referred clients back to the hospital without providing information about the issues or concerns,

> *"They may want to tell us the things we are trying to implement is not going to work in my environment, but they are just not saying it to us and that's the most frustrating thing because we only look at how the patient responds to us in the hospital...so those cases that come back to us or ask us to see again after they are discharged are usually because we don't have enough information of how the patient behaves in the home." – SMHP 1*

Others stated that long-stays in the hospital is not a ideal situation due to physical limitations of the environment and restricted schedules that people with ID have to adhere to. They felt that staying at the residential insituation is the better alternative than the hospital when FCs are unable to bring them home because of fewer restrictions,

> *"It's like everybody is "locked up" in one small area in the hospital for 45 people staying together and at certain time, you have to go to certain places. Certain time you have to go back to your dormitory to sleep. You don't have that much freedom." – SMHP 2*

> *"Caregivers are still involved, they visit the homes and bring them out for outings so in the sense, certain issues or certain concerns of the care are addressed. They have accommodations, they have their meals met, their daily care, they can live in a place with safety and live with dignity and quality of life." – SMHP 7*

Some SMHPs considered the support staff in nursing homes *"well-trained"* with appropriate strategies to deal with behavioural issues,

> *"That's the advantage of the nursing home. They can help patient with behavioural issues, they know what kind of positive or negative behaviour, and how to reinforce the positive behaviour, how to minimise or reduce the negative behaviour." -SMHP 4*

However, others felt that there is an inconsistency in the level of training that impact on their attitudes and perception of people with ID,

> *"The staff in disability home or nursing home still lacks training. They don't have much experience in taking care of this group of people. They will think that they are just kids, they will pity them." - SMHP 6*

The lack of resources and time in the residential institution were brought up by SMHPs, *"Some of the residential staff at the homes struggle to be trained due to manpower issue. Because if you want to train them, it takes a lot of hard work" (SMHP 8)*. Despite that, SMHPs noted an improvement in the level of commitment and work after the staff has been trained. In summary, SMHPs stressed the need to engage with residential support staff to provide on-going training that can improve their attitudes and competency,

> *"Some support staff are quite passionate and do more than what they are supposed to do after training. They will really set out goals, missions and make sure that they prepare for their clients and that their clients can carry them out eventually. There's a difference but I think both parties should work together continuously more often." – SMHP 8*

Main theme 3: Disempowerment of service users

The third theme concerns the treatment of people with ID in hospital and the community. This theme outlines the barriers towards empowering the people with ID and SMHPs' experiences and views on integrating people with ID in the community.

Sub theme 1: "They should be given more choices"

Most of the SMHPs concurred that adults with ID should be provided with opportunities to be more independence and control over their wants such as expressing their choices and wants, *"Because he can think, he can verbalize to you what he wants, what he prefers so if that's the case, we should respect the patient's feelings, we should give enough autonomy" (SMHP 2).* However, adults with moderate to severe ID are often presumed to lack capacity to make decisions related to their care and SMHPs then ignore their views, instead discuss the care plan with family members,

> *"They lacked mental capacity to decide their own care so the management plan, we usually discuss with the family members and because most of them do not have the capacity to decide the treatment, they don't even understand what type of treatment that they are receiving, so the care and implementation of the treatment is mainly lies with the family members."*
> *– SMHP 4*

SMHPs would try to find a common ground between the choices of the person and their family members,

> *"Caregivers would like to have certain plans. Patients may not want it. So what's important is having a conversation on this with both of them, see what will be in their best interest and to allow our patients and our caregivers to leave with an enhanced quality of life." – SMHP 6*

In some situations, SMHPs reported taking on the additional role of abitrator to decide on the best interests of the person with ID by considering the safety issues and risks involved for the person,

"I would always weigh the risks, safety factors, so is there any risk at the moment that needs to be targeted...that's always a priority. Then after that, I would try to look at what patient says, what family says, and then I will kind of assess based on the current situation, which one is important, which is affecting the patient's life more." – SMHP 3

Some found it emotionally difficult to deny their requests or choices,

"Breaking up that news is a bit difficult for me if you asked me in terms of their wants." - SMHP 5

Despite their strong views on respecting the autonomy and capability of the person with ID, SMHPs felt that in reality, adults with ID have very little choice in where they wish to go after being discharged from the hospital or in having interpersonal relationships with the opposite gender. They noted that FCs may restrict the leisure opportunities of their relative due to perceived fear and wanting to protect them*, "I think there are also in terms of leisure time. I see sometimes there is a restriction to it, they are a bit like cocoon, they stay in their comfort, safety zone for their leisure time" (SMHP 5),*

"Sometimes, patients really don't have much choices on their discharge plans." – SMHP 6

"They (people with ID) in their adulthood are very motivated to have romantic relationships, to have partners...but I think the difficulty is that sometimes to get them back to reality that they may or they may not end up in a romantic relationship." – SMHP 5

SMHPs reported concerns that MMHPs without any knowledge of ID or prior work exposure might have negative attitudes towards people with ID, ascribing the behaviours to their personality and believing that they are unable to recover from their MH problems. This was raised in the context of restraints being used when mainstream staff are unable to treat the person approriately due to lack of resources and fail to understand the root causes of the behaviour,

> *"Sometimes, they will think that their aggressive concern is part of the personality. They may feel that patients with ID always will have challenging behaviours. They will also be thinking that this group of people is a burden of the society and hopeless." – SMHP 6*

> *"In order to ensure safety, they need to make sure no injuries. They may choose to use restraints. These doesn't really help. I don't think it's helpful for the clients but because they have limited manpower and they are not sure of what's going on with the client so it's very hard for them to manage." – SMHP 8*

Sub-theme 2: "The public just want to get away from them"

SMHPs reflected that in their societal culture, adults with ID and MH problems are not provided with adequate support to allow them to integrate in the community, *"Our local culture is not so accommodating. You see even our patients' right… They are not really, I won't say well respected... They are not really respected. People have a bias against them." (SMHP 2).* This stigmatisation sometimes created challenges to find appropriate community resources for their SUs and FCs can become despondent following multiple rejections to access community services,

"Some of our patients have behaviours so they are restricted from community services. They may cause a bit of caregivers to feel dejected. Rejection. They feel they are tired of navigating the services" – SMHP 7

Thus, SMHPs summarised the public stigma towards people with ID succinctly, describing how this group remains ostracised and segegrated from the community, *"The public just want to get away from them and look at them very briefly. They don't support people with ID to stay in the community, rather prefer them to stay in the disability home or hospital or stay at home. Try not to mix up with the public." (SMHP 6).* People with ID, as noted by SMHPs, are sometimes treated harshly by the public when the public perceive their behaviours as a nuisance and dangerous. SMHPs recognised that FCs avoid bringing them out in the community as a way of coping with the stigma,

"I think in terms of public attitudes, some can be very not welcoming...like when they make noise in the bus...so sometimes they will be told off to alight at the next bus stop. Whenever they have this aggressive behaviour, usually the police will be involved, handcuff them and bring them because of aggressive behaviour, so I think that sometimes cause trauma for the patient." – SMHP 5

When discussing the attitudes towards people with ID, SMHPs often referred to their societal culture, wishing it is more forgiving and allowing people with ID to perform at their own pace. This was especially pertinent when it came to discussing work employment opportunities,

"Sometimes I feel the expectations are too high, especially those in workplace, they are expected to perform in a certain manner, such as well and good as ourselves. So I think the understanding of the public, in terms of their expectation needs to be moderated a little. To understand that sometimes they can't perform to a certain extent, they are not the best

worker but if you are willing to provide your support, give them time to learn and help them to adapt in the workplace, I think they can still grow to be a good worker." – SMHP 8

The majority of the SMHPs acknowledged more work is required to change public perception towards this population, however they note that current knowledge and understanding of disability in Singapore is new and developing, thus are hopeful that there would be a positive change in societal attitudes and perception through research and public campaigns,

"The field itself, the disability field itself, even the community's understanding and acceptance of person with special needs, different needs, is I would say, it's still developing. The perception or views of the community may be not fully informed. For people coming in this field, to also realize and understand that what may be the further work to be done other than the interpersonal work and the community engagement." – SMHP 7

"I think the stigma exists and from my experience, general public may even have more negative view for patient with ID. we need to address the stigma, that's why we have a lot of campaigns to address the stigma." – SMHP 4

"Quite difficult. Must really change people's mindset. Having public education, we must let everyone understand people with ID. To help them, support them to stay in the community." – SMHP 6

One of the SMHPs suggested that future collaborative opportunities with the community partners may facilitate smoother transition of care and increased participation of people with ID in the community,

"I would like to do more collaboration with different organisations especially community, to see how we can include our clients into the society rather than staying at home or in the hospital." – SMHP 8

Main theme 4: Improving clinical practice

SMHPs discussed ways to improve their clinical practice and service delivery in this theme. They shared that they had insufficient time available for intervention work and would like to have more time to carry out their work with this service group due to the complexity of their MH problems,

"More time is needed…this kind of work cannot be rushed towards looking into some things." – SMHP 5

"Time would definitely be needed. That would be the challenge that we balance. Time limited intervention in the tertiary institution vs knowing that some of these issues are long standing, engrained learnt behaviours."– SMHP 7

In addition, having more support from management to improve the hiring and retention of the staff as a high turnover rate can affect their training opportunities as well as the therapeutic relationship with the SUs,

"The high turnover will cause inconsistency because different therapists have different approach and the ID patient, they have poor adjustment, they may not be able to cope well if there is a sudden change." – SMHP 4

"It's usually peer support rather than mentoring or supervision because the turnover rate of the staff is quite high, so you don't really have a lot of experienced staff here to support you with your clinical development." – SMHP 1

For all SMHPs, the ongoing supervision and consultation with other colleagues in the team are useful in helping them to sharpen their clinical skills and think of alternative strategies to work with the SUs, *"What helped me was supervision definitely on getting some guidance on how to manage these cases, try to understand it from other views so through supervision, I get to understand more points and working in a multi-disciplinary team, so I get to bounce ideas of my colleagues" (SMHP 3).* Some of the SMHPs felt that there is a need to identify potential staff who were keen to work with this population to have early work exposure and opportunities for professional training,

> *"We should have a kind of special training for the clinicians who are willing to work with the ID patient, probably provide more training opportunities overseas and to support clinicians who want to work with ID patients in the future to have some kind of training in the overseas centres who have experience looking after those patients." – SMHP 4*

SMHPs felt that having a support group would be useful to allow them to express their emotions in a safe place without the fear of being judged. Having a more experienced colleague as mentor or providing emotional support to newly graduated SMHPs would be helpful to ensure that they do not become overwhelmed and emotionally burdened with the demands of the work,

> *"I think support group is really needed for the clinicians also...this support group, just to not to talk about any goals but to vent out for emotional support." – SMHP 5*

> *"If it's a new graduate, they may have difficulties with self-care because they are so focused on their clinical work and clinical improvement and performance that sometimes they may lack self-care." – SMHP 1*

Besides focusing on professional training, ongoing supervision and management support, SMHPs shared that new services could be developed such as counselling services for family members to help them understand their feelings about and reactions towards their family members,

> *"Helping them to share some of their psycho emotional concerns, thoughts, regarding the caregiving difficulties that they have. Sitting with them and helping them to process that. Providing information, care and counselling for caregivers." – SMHP 7*

They discussed about how the services can be adapted to focus on empowering people with ID to make choices. They felt that there should be paradigm shift in how they provide services, for example moving towards *"supporting them to make a decision by themselves rather than just making a decision for them. We must find out what is the best interest" (SMHP 6).* They shared that the service delivery model should consider the social relationships of people with ID, which is currently difficult for them to address due to a lack of awareness, *"I think that is my difficulty in terms of working...the social relationships...it's very hard to convince or tell people actually what are you dealing with or what is this person like?" (SMHP 5).* One of the SMHPs mentioned an overseas expert who talked about facilitating autonomy and decision-making in adults with ID and raised concerns whether it is acceptable within their culture,

> *"We even invited an ID expert from UK, he said in his nursing home kind of thing, the patients can do a lot of things, go for sports, go out to buy a drink and smoke. He was even sharing that 2 mild patients, a male and one female, they ask him can we make love tonight? Then he answered... you are big enough, you can make your own decision. I was very shocked to*

hear that. I don't think this is possible to have one ward with males and females are together." – SMHP 2

Discussion

This study provides a unique insight into the experiences of SMHPs working in specialist MH ID service for adults with ID and MH problems. Individual interviews with this specific group of SMHPs in Singapore provided a deeper understanding of the specialist MH ID service provision and their experiences, views and feelings working with this specific population. TA revealed four main themes which were 1) Role of specialist mental health professionals, 2) Ensuring continuity of care, 3) Disempowerment of service users and 4) Improving clinical practice.

This study is unique in exploring the role and work responsibilities of SMHPs in an Asian context. Most current literature is focused on MHPs working in western countries with individualistic values that promote autonomy and empowerment in people with ID. MHPs in Singapore encounter challenges when adopting westernised philosophies of individualism and normalisation in their practice as FCs are the ones who have the final say on how people with ID should live their lives. The current findings indicate that high levels of stigma can affect MHPs' efforts to integrate people with ID into their communities and when family members are unwilling to continue caring for them, the preferred option is often admission to a residential home, as a way of segregating them. Recent research in the United States reveal that states with a high level of disability prejudice have higher numbers of people with ID being institutionalised and spent more funding on institutionalised care (Friedman, 2019).

Strong negative feelings and uncertainty were reported among SMHPs when they first started working in specialist MH ID services. They reported the work to be challenging. These findings are in keeping with previous research findings which have identified negative feelings among HCPs when working with this population (Lee & Kiemle, 2015; Storey et al., 2012). The current findings indicate a gradual improvement in work satisfaction and a reduction in negative emotions. A possible explanation is that SMHPs in this study develop their skills and competency over time as a result of constant contact and exposure working with this group, which lead to improved attitudes and reduced levels of anxiety (Scior, 2011).

In the current study, SMHPs had relatively short (ranging from one to six years) work experience with people with ID which can be explained by the recent (2011) start date of the service. Narratives of SMHPs describe high staff turnover which may suggest difficulties in hiring and retaining staff working with this population and may be another reason why the participants in this study had not worked for long in ID services. Lack of organisational support is a common reason for staff's lack of work satisfaction and affects the quality of ID services (Capri & Buckle, 2015; Hermsen et al., 2014; Innstrand et al., 2004; Kernohan, 2016). It is, therefore, imperative that hospital management and policy makers listen to MHPs' concerns about their high work demands and provide adequate resources to support them through, for example, making changes in the recruitment process and providing interventions to address stress and burnout (Edwards & Burnard, 2003). However it should be noted that despite the introduction of peer-supported programmes, there is a low utilisation rate among MHPs in Singapore, suggesting a poor level of awareness and/or perceived fear of being penalised (Chan et al., 2012). Therefore, hospital policy makers should take steps to initiate changes in work culture, such as making it more acceptable for MHPs to utilise these services and increase the awareness of such services and allow them

to access these services confidentially, without negatively impacting on their work performance.

Working in a multidisciplinary team is a distinct feature of SMHP's work in the specialist MH ID service and it was viewed positively among the participating SMHPs. They reported that they were able to engage in problem-solving with other SMHPs in varying specialities as a team when facing uncertainty in their work. Moreover, they valued a holistic approach towards care planning for people with ID with each member of the team taking on specific roles to address the various needs of the person. Other studies also indicate that using a multidisciplinary approach is likely to help people with ID feel that their concerns are valued and addressed, and encourages them to be more participative in their treatment plan (Johnson & Viljoen, 2017). Indeed, other research findings have revealed that a lack of multidisciplinary approach is associated with higher levels of psychotropic medication being prescribed as a result of lack of professional input from non-medical staff (Niven et al., 2018)

Almost all the SMHPs recognise the importance of building rapport and a therapeutic relationship with people with ID. They stress that having an interest in and passion for working with this specific group are more important than having competence and knowledge. Most research has focused on the competency and training needs of MHPs to increase their ability to care and manage the behavioural problems of people with ID without considering the therapeutic aspects of building relationships (Sajith et al., 2017; Sajith et al., 2017; Werner et al., 2013; Werner et al., 2013; Wilkinson et al., 2012). Further developments in the specialist MH ID service structure include having stronger consideration for non-pharmacological approaches and a stronger emphasis for SMHPs to focus on building trust and therapeutic rapport with them which could affect their

motivation and readiness for change during the treatment process (Bonell et al., 2012; Lewis et al., 2016; Mason, 2007; Willner, 2005).

Difficulties with communication is often identified as a barrier towards effective engagement and a trusting relationship between people with ID and their service providers (Richardson et al., 2006; Sowney & Barr, 2006). The findings in Chapter 4 highlight similar difficulties experienced by MMHPs to communicate with people with ID. Research indicates that HCPs make adaptations to their clinical practice to meet the communication needs of people with ID (Goldbart et al., 2014; Melville et al., 2006) which the SMHPs in this study sought out do using non-verbal communicative approaches to increase engagement and facilitate therapeutic relationships with people with ID. What is interesting in this study is the implicit attitudes and views of SMHPs on their relationship with people with ID, referring them as *"patients"*, suggesting a hierarchical structure or power imbalance between them and the SUs. This power imbalance may have an impact on the therapeutic relationship with people with ID as they may easily acquiesce to treatment without being fully informed (Cheetham et al., 2017).

There is also an assumption that people with ID are dangerous and an emphasis on staff having to be vigilant when working with them as highlighted by SMHPs in the study. This is a common phenomenon found in inpatient psychiatric settings in hospitals where the people with ID are viewed as having an 'illness' and needing to be handled or care for with necessary precautions (Campbell, 2013; Cheetham et al., 2017). Literature suggests that staff's attitudes towards aggressive behaviours have an negative impact on how they respond to them such as using coercive measures or psychotropic medication (Knotter et al., 2013; Perry et al., 2018). Jahoda and Wanless (2005) found that staff form negative

perceptions of their clients following episode of physical aggression with them which negatively affect the interpersonal relationship. Therefore findings from the literature could reflect the emotional reactions of SMHPs following their encounters of people with ID who display aggressive behaviours towards them.

Housing needs becomes a significant issue when FCs are no longer around to continue caring for adults with ID (Harvey et al., 2012; Shaw et al., 2011). On discharge from the hospital, people with ID are often transferred to residential institutions when family members no longer wish or able to care for them. In this study, SMHPs consider the views of FCs instead of consulting people with ID themselves regarding their living arrangements. There is a wrangle between SMHPs' views of promoting autonomy and empowerment in people with ID and the practical limitations in achieving this in a collectivist culture in which the family unit plays a crucial role in making decisions for the person. Kanter (2012) argue that people with disabilities have the legal right to decide where and with whom they wish to live in the community. However, due to more stigma and less support for people with ID compared to those with physical disabilities (Werner, 2015), coupled with a strong cultural preference for housing them in residential homes and being segregated from the community (Scior et al., 2010), choice for people with ID is restricted. The lack of available housing and supported accommodation are likely to limit the options for people with ID to have a presence in the community. SMHPs find it difficult to challenge the cultural norms and instead choose to work within the cultural boundaries until such time when the society is more readily accepting of this group living in various kinds of community-based housing based on their needs.

Living in residential institutions becomes the only alternative for people with ID when SMHPs realised that FCs are unavailable to take them back after discharge from the hospital. SMHPs highlighted the misconception among FCs who view that MHPs are more competent and equipped to take care of their relative and as such may not wish for them to be discharged home. This is likely stemmed from the poor level of knowledge among FCs that affect their ability and confidence to take of their relative. FCs experience a loss of control over their lives when they are unable to manage the behaviours which contribute to their high psychological distress (Dawson et al., 2016; Waite et al., 2017). Hence, it could be possible that FCs in Singapore may lack the coping strategies to address their emotional difficulties following their relative's admission to specialist MH ID service for treatment and fear of being re-traumatised when their relative displayed the same behavioural problems after being discharged. SMHPs did not report of offering psychological interventions for FCs, thus it is recommended for SMHPs to understand the emotional struggles that FCs are experiencing and provide resources for them to seek psychological help and improve their well-being.

An important component of their work is collaborating with residential support staff and providing them with training and supervision to increase their skill competency and willingness to care for people with ID and MH problems after they are discharged from the hospital. Research findings in an East Asian context have shown the effectiveness of staff training to change attitudes towards facilitating the self-determination of people with ID (Wong & Wong, 2008). SMHPs noted the mixed reactions from support staff and a lack of collaborative practice and understanding between both parties. The organisational culture (Hatton et al., 1999) of the residential institution may affect the level of engagement between support staff and SMHPs (Rose et al., 2006). Support staff's attributions of the

challenging behaviours in people with ID have been found to have an impact on the quality and delivery of care (Williams & Rose, 2007), which may also account for staff's unwillingness to work with SMHPs. Applied psychologists have identified the importance of building therapeutic relationships with staff in a residential setting and noted that some staff were hesitant to share information with them (Stenfert Kroese & Smith, 2018) which was similarly observed by the SMHPs in the current study. The authors additionally identify that organisational culture may be a barrier for implementing changes in the provision of care for people with ID. Therefore, SMHPs need to consider interpersonal and organisational factors when working with support staff in the community to order to implement behavioural programmes successfully.

In this study SMHPs spoke of equipping support staff with skills to deal with challenging behaviours but there was no mention of training the support staff in the basic understanding and screening of MH problems or carrying out group-based interventions to manage MH problems. This lack of consideration may be due to the role of support staff which in Singapore is to provide only basic care to people with ID and not to address their MH symptoms, indicating a clear delineation of roles between residential support staff and healthcare professionals. Perhaps SMHPs should offer more MH training to residential support staff to carry out group based therapeutic interventions and MH screening, thereby decreasing the need for frequent hospital consultations and admissions which could translate into an overall decrease in work demands and healthcare costs (Costello et al., 2007; Stimpson et al., 2013; Woodward & Halls, 2009).

SMHPs identified a common challenge to provide services that promote autonomy and empowerment in adults with ID. Findings from cross-cultural research reveal that non-

western countries, when compared to western countries, have less favourable attitudes towards empowerment of people with ID and are less inclined to provide the same rights to them as to the general population (Benomir et al., 2016; Patka et al., 2013; Scior et al., 2010). These findings further extend to non-western people having negative attitudes and views regarding sexuality issues and sexual rights in people with ID as compared to westerners (Sankhla & Theodore, 2015). Across the world, people with ID have fewer social networks and lead a more impoverished lifestyle than the general population (Lippold & Burns, 2009). SMHPs in the current study mentioned the restrictions imposed on people with ID in regard to choosing whom they wish to have a romantic relationship with. They felt uncertain and ill-equipped to transfer principles of SRV within their own cultural context in their work with people with ID. The role of culture appears to have a huge impact on the public and MHPs' attitudes towards the sexuality of people with ID (Ditchman et al., 2017; Meaney-Tavares & Gavidia-Payne, 2012). Hence, it remains a challenge for SMHPs to find ways to further improve the specialist MH ID service in order to address the quality-of-life domains of self-determination and interpersonal relations in people with ID (Morisse et al., 2013).

Implications of findings

The findings of this study indicate that besides providing more training, opportunities for overseas work experience and supervision by experienced clinical staff, there is a need to move beyond improving the competencies of healthcare professionals and instead consider policies to improve the hiring and retention of staff, as well as ways to enable SMHPs to build genuine therapeutic relationships with people with ID. Government agencies may have to consider the social and housing needs of people with ID instead of narrowly focusing on their health and employability. This could mean having public campaigns to

create awareness in the public of their human rights. Freedom to choose could be achieved by incorporating the views of people with ID in their own care plans, improved community presence and participation (O'Brien, 1992) by developing support plans for people with ID to facilitate integration, community participation and increasing their social network.

Outcome measures that are comprised of interpersonal and empowerment domains for people with ID could be developed to evaluate the progress made in these areas (Flynn et al., 2017). Public stigma towards this group may be improved by sharing case studies of adults with ID leading normal and fulfilling lives after recovering from their MH symptoms, such as being employed or interacting with other people in activities in the community. MH screening and assessment checks for early detection and management of MH problems should be introduced for people with ID living in the community or residential settings (Robertson et al., 2011). Support staff and mainstream primary healthcare professionals can take a more active role in screening and assessment of MH problems with support and supervision from experienced ID MH professionals. Community-based therapeutic interventions should be made available in residential institutions and support staff should be equipped with the necessary skills and competency to manage and address the MH issues for the residents with ID (Dodd et al., 2013).

These results show that SMHPs work in a multi-disciplinary team which also involves FCs and support staff in the community as stakeholders instead of working one-to-one individually with people with ID. Therefore, SMHPs could consider more ways to involve the FCs and support staff in the community through providing training, psychological interventions or assistance in evaluation of service provision in the community. This mean that SMHPs would need to build therapeutic relationships with different stakeholders to

ensure that the treatment plan is mutually agreed between all of them and they are willing to implement the intervention strategies across different settings. Hence, having the necessary interpersonal characteristics, such as honesty and warmth are very much more important for building a genuine and trusting relationship rather than having the pre-requisite skills and knowledge. Thus, hospital policy makers need to focus more on these desirable qualities when considering suitable candidates to work in this field and this could be achieved through shadowing them at work, placing a higher emphasis on these interpersonal traits as part of their job competency and obtaining references from their previous work, volunteer or practicum experience.

Conclusions

This study has allowed SMHPs to share their experiences of providing specialist MH ID service for adults with ID in Singapore. MH problems of people with ID are managed in a multidisciplinary team of SMHPs from varying specialities. Findings of the study provide insight into the impact of stigma and culture on current services, the difficulties in working with FCs and community partners and the limitations of current services in empowering people with ID. SMHPs offered suggestions to improve the current services and stressed the importance of changing public perception to facilitate inclusion of people with ID in the community. Their recommendations will require a sound evidence base and collaboration with community and governmental agencies. Nevertheless, this research has shown that SMHPs in Singapore have already made significant changes to address the MH problems of people with ID and lays a foundation for evidence-based practices to be developed to meet their psychological and social needs.

The next study, presented in Chapter 6, describes a qualitative study of FCs, their experiences of providing care and views of the specialist MH ID service.

Chapter 6: Study 3 – Family carers' experiences of providing care and views of services for their adult relative with intellectual disabilities and mental health problems

Introduction

Caring for a person with ID can become an extra burden for their FCs as the person grows older (Baker et al., 1997), especially when they exhibit MH and/or behavioural problems which likely contribute to high levels of stress and negative emotional reactions in FCs (Maes et al., 2003). Often, this increased difficulty in managing their relative's behaviours impels FCs to seek external help from HCPs in MH services.

FCs in a number of countries have reported on unpleasant experiences when accessing generic disability services for their relative with ID which include a poor relationship with staff, poor coordination between various services, lack of expertise among staff and difficulties in accessibility (Llewellyn et al., 2004; Man & Kangas, 2019; Nicholas et al., 2017; Redmond & Richardson, 2003; Wodehouse & McGill, 2009). FCs of relatives who received specialist MH ID services in the UK have reported that staff were more friendly and able to clarify information for them whereas those who accessed mainstream MH service reported feeling disempowered, felt a lack of trust and were not consulted during the treatment process (Longo & Scior, 2004; Scior & Longo, 2005). FCs noted HCPs in mainstream UK MH services are not willing to make reasonable adjustments and have a poor knowledge of social services for people with ID (Ali et al., 2013).

Literature suggests that FCs struggle to understand the MH problems of their relative with ID and report to experience feelings of grief and helplessness (Faust & Scior, 2008; James,

2013). Another study found a strong association between the presence of MH problems in relation to the quality of relationship between FC and their relative (Larson et al., 2011). Presently, there is no research that explores the experiences of FCs of adults with ID within the Singapore context. It remains unknown how this group views their caregiving roles and makes sense of the MH problems of their relative with ID. Moreover, MHPs in Chapter 4 and 5 talked about the stigma that FCs and individuals with ID experience in Singapore and how FCs are affected by discrimination and prejudice. Research has shown that high levels of caregiving burden can contribute to caregiving stress and depression with lowered self-esteem in FCs (Kim, 2017). Additionally, little is known regarding how FCs in Singapore view the specialist MH ID services for their relatives with ID or about their experiences when their relatives receive such services.

The present study therefore aims to 1) provide a unique perspective of how Singapore FCs view their relatives' MH problems and 2) provide insight into their experiences of specialist MH ID services for their adult relative with ID and MH problems.

Method

Participants

Seven women and two men with ages ranging from 41 to 73 years (median age 64) were recruited in a tertiary psychiatric hospital where their adult relative received specialist MH ID service in Singapore. Four Chinese, four Indian and one Malay participant were interviewed. Six of the participants attained O-Levels, two attained a post O-level vocational qualification, that is Diploma, and one completed primary school education only. All of their relatives with ID (except for participant 7) identified themselves as parents while Participant

7 identified herself as a grandparent. The adult relatives with ID were aged between 20 and 41 years old (median age 29). Five of the relatives were diagnosed as having mild ID while the others had moderate ID with speech and adaptive impairments. Five of the relatives had a co-morbid diagnosis of ASD while one of them was diagnosed with Down Syndrome. The most common MH problems of their relatives reported by the participants were depression, psychosis and anxiety. FCs also reported challenging behaviours including hyperactive and aggressive behaviours.

Participants will be referred to as Family Carer (FC) with the corresponding number allocated to them in Table 6.1 to protect their confidentiality.

Table 6.1: Demographics of Family Carers

Participant (FC)	Age	Gender	Ethnicity	Highest education level	Age of relative with ID	Relationship of relative with ID to carer	Neurodevelopmental Diagnosis/ Mental Health Problems
1	66	F	Chinese	Diploma	33	Daughter	ID (Mild), Down Syndrome Depression, social anxiety, school refusal
2	62	M	Malay	O-Levels	29	Daughter	ID (Mild) Psychosis, aggressive behaviours, anxiety
3	73	M	Chinese	O-Levels	34	Son	ID (Mild) Hyperactivity, aggressive behaviours
4	41	F	Indian	O-Levels	22	Son	ID (Moderate), ASD Hyperactivity, aggressive behaviours
5	70	F	Chinese	Primary	41	Son	ID (Mild) Schizophrenia

6	50	F	Indian	O-Levels	20	Son	ID (Mild), ASD Depression, aggressive behaviours
7	72	F	Chinese	O-Levels	21	Granddaughter	ID (Mild), ASD Depression, psychosis, avolition
8	64	F	Indian	O-Levels	29	Son	ID (Moderate), ASD Hyperactivity, aggressive behaviours
9	56	F	Indian	Diploma	22	Son	ID (Moderate), ASD Depression, hyperactivity, aggressive behaviours

Interview Schedule

The interview schedule in Table 6.2 shows examples of open-ended semi-structured questions that allowed participants to share their experiences freely with minimal input from the researcher. The questions in the interview schedule were based on relevant findings reported in the research literature in Chapters 2 and 3, and previous studies with MHPs in Chapter 4 and 5. The content of the interviews focused on exploring the participants' experiences taking care of their relatives with ID, their views and beliefs regarding their relative's MH problems and what prompted them to seek specialist MH ID service. The participants were also asked about the impact of their relative's MH problems on their lives, the challenges and rewards of their caregiving role and what kept them going. Lastly, they were also asked about their experiences of interacting with SMHPs, their views regarding the specialist MH ID service and recommendations for service improvements. The questions were discussed with the academic and clinical supervisors for content validity. Prompts were used to facilitate the participants to make meaning based on their

experiences and reflecting on their emotions that they experience when taking care of their relatives. More information of the interview schedule can be found in Appendix 11.

Table 6.2: Interview Schedule of Family Carers

Example of questions
1. Can you tell me about your relative?
2. Can share how did your relative came to receive specialist MH ID service?
3. What is like taking care of your relative?
4. How do people respond to your relative?
5. How do professional staff respond to your relative?
6. How do you find the services?
7. What makes someone suitable to work with people with ID?
8. What is it like receiving support from healthcare professionals when taking care of your relative?
9. How can healthcare professionals be helped to do a good job in supporting your relative?
10. What is your hope for your relative?

Procedure

A qualitative research design was used to address the aims of the study. The research was conducted with the help of a clinical supervisor working at the hospital. Following ethical

approval (Chapter 4, Method section, Page 132, Appendices 24 and 25), potential participants were identified by the clinical supervisor who initiated the first contact by distributing the invitation letter (Appendix 8). The letter contained brief information about the aims of the study and contact details of the researcher if they wished to participate in the study.

To increase the recruitment rate, the clinical supervisor also asked the MHPs based at the hospital to distribute the invitation letter to the participants when they brought their relatives for consultation. With permission from the MHPs, the researcher approached the FCs to explain the nature of the study and rationale of conducting this research. FCs were asked if they wanted to take part in the study and provided their contact numbers to arrange an interview date. They were also provided with an information sheet and consent form (Appendix 9).

Written consent was obtained from the participants before starting the interview. Participants were asked about their demographic information before the interview (Appendix 10). The interviews were carried out at the participant's house and took between 30 and 40 minutes. Interviews were conducted mainly in English. Some participants spoke in Mandarin when using specific phrases or words which were translated in the transcripts by the researcher who can understand and speak the language. Audio recording was used during the interview session. Participants were provided with a shopping voucher as a gesture of appreciation for taking part in the study.

Data Analysis

Interpretative Phenomenological Analysis (IPA)[2] was chosen to analyse the transcripts based on Smith et al. (2009). This analysis was appropriate for this study as it allows the FCs to be viewed as experts regarding their own experiences, thus allowing them to provide detailed stories or accounts and by doing so, FCs can draw on their assumptions, beliefs and thoughts to make cultural meaning and sense of their lived experiences.

An additional advantage of using this approach for data analysis is that it allows the FCs to describe the narrative accounts of their experiences, i.e. what happen to them, and its emotional impact, i.e. how do they feel. In doing so, participants attempt to evaluate and explain their experiences as a way of making sense and meaning of their experiences. It also offers FCs to highlight important aspects or parts of their own experiences, i.e. what struck them as the most important elements, without much input from the researchers and hence allows for flexibility in developing new ideas or themes that are grounded on their experiences. In summary, the use of IPA regards the particular experience of FCs as unique, situational and personal, hence advocates inferences of claims and findings that are grounded in the collected data.

The approach involved reflective engagement with the narratives of the participants by 1) listening to what the participants were saying about their experiences and 2) bringing awareness of the participants' thoughts and emotions during the interview as well as the researcher's own views and thoughts as he interacted with them to understand more about

[2] IPA draws on three theoretical key concepts of phenomenology *(how people make sense of their experiences)*, hermeneutics *(how the researcher's beliefs and views attempt to shape and make sense of participants' experiences)* and ideography *(focus on lived experiences of participants within their own distinct socio-cultural context).*

their experiences. This was carried out according to the stages described by Smith et al. (2009) which were summarised in Table 6.3.

Table 6.3: Stages of IPA from Smith et al. (2009)

Step		Description
1	Familiarisation of the data	Multi-readings to immerse myself in the individual transcripts, made notes to record down my thoughts and ideas, focused on participant's experiences during the analysis and noted down own subjective assumptions and perceptions.
2	Developing initial notes or comments	I made comments along the side of the transcripts. First, I noted down how participants described their accounts narrative using key words and phrases and how they made sense to them. Second, I noted down the language used by participants that involved paying attention to their tone, emotions and choice of words they used to emphasis or play down parts of their experiences. Last, I noted down how participants reflected and tried to understand their experiences, identified any conceptual ideas that participants describe regarding their own experiences
3	Developing emergent themes	I wrote down short sentences or phrases that captured the important aspects or essence of the transcripts based on the comments. The short sentences or phrases form emergent themes that are based on my interpretation of participant's experiences as well as participant's own narrative and interpretation of their experience
4	Forming master themes	I looked for connections or patterns across the emergent themes. I placed all the emergent themes together, labelled and categorised them to form main themes. The main themes consisted of similar patterns of meaning found across the transcript. Some emergent themes were not used as it did not fit with the master themes.

5	Continue with the next transcripts	I continued with steps 1 to 4 on the next interview transcripts until all of them were completed
6	Develop master themes across the interviews	I placed all the main themes and sub-themes of all the transcripts together in word document. I began to look for similar connections and patterns across the different participants. Similar emergent themes across the transcripts were colour-coded together and relabelled as sub-themes. Master themes were then developed by grouping similar sub-themes together. Similar main themes were also colour-coded together to form master themes. Quotes were identified from the participants that illustrated the sub-themes.

The analysis was primarily carried out by the researcher. He read each individual transcript repeatedly to immerse himself with the data so that the participants became the focus of the analysis. Initial notes and ideas about the transcripts, behavioural observations about the participants during the interviews including their emotional expressions, their tone of voice and use of language were noted to ensure that their experiences remained the focus of analysis. In addition, anything of interest within the text was noted down in the right-hand column of the transcripts to increase familiarity with the data.

Three types of comments were noted down in the transcript. Firstly, descriptive comments such as descriptive recall of experiences, encounters with MHPs and relationships with their relatives were noted through key words, phrases, short sentences of explanation. Secondly, linguistic comments were noted that includes the use of their language, pauses, emotions, repetitions and metaphors. This also includes the words that the participants used within their own cultural context to help them make sense of their meanings in their experiences

to convey their emotional state to the interviewer. Lastly, conceptual comments were noted that involves interpretation of the data through discussion, reflection and application of psychological theories to help the researcher to understand what the participants were going through. The researcher drew on his personal reflections from his professional knowledge working with people with ID as well as his cultural knowledge to understand how culture influenced the participants to shape and define their experiences. At the same time, thinking about the context of the participants and talking to MHPs in Chapter 4 and 5 helped the researcher to have a clear understanding of the issues that the participants faced. The researcher also reflected on the possible reasons why certain issues were said and held more importance for the participants than other issues. Lastly, the conceptual comments included thoughts of how the researcher tried to link the issues and key points together in the whole transcript to form a coherent narrative.

The process of developing emergent themes and subsequent stages of analysis were similarly carried out as described in Chapter 4, method section under "Thematic Analysis" (Page 133). Initial codes consisting of short phrases or key terms were assigned a number and written on the left-hand column of the transcripts. The initial codes in the transcript were printed and separated into individual strips of paper which were categorised according to similar themes, patterns and interpretations. Connections between the codes were taken into consideration to help the researcher makes sense of the given phenomenon. There was a frequent shifting back and forth from the participants' account of their experiences to the researcher's interpretation of their experiences to attempt to understand the meaning that the participants attributed to them. Master themes with corresponding emergent themes were developed into a table and this process was repeated across the other transcripts.

The final stage of analysis involved compiling all the master themes and emerging themes from the transcripts into a separate Word document. The same process of categorisation was carried out and some were relabelled to better capture the meaning of the participants' experiences. A final table of super-ordinate master themes with corresponding sub-themes was developed and relevant quotes were extracted from the raw data to illustrate the themes. More information on the data analysis process and participants' quotes can be found in Appendices 12 and 13.

Credibility checks

The same credibility checks were applied according to the Lincoln and Guba (1986) framework of trustworthiness described in Chapter 4, Method section under the "Trustworthiness in analysis" (Page 136).

As IPA focuses on the idiographic exploration of participants' experiences, Smith et al. (2009) recommend a small sample size with participants having similar experiences. Therefore, the number of participants (n=9) makes it suitable to achieve thematic saturation. The transcripts and stages of the IPA were verified and audited by the academic supervisors. There were regular discussions with them to discuss on the possible interpretations of the data and coding of the themes to ensure consistency. The quotes were also verified by the supervisors to ensure that it represented the essence of the participants' experiences. The final table of superordinate themes was discussed with the clinical supervisor to ensure good level of agreement.

Information about the description of the demographic profile and data collection procedures were carefully documented to ensure transparency of the findings. The clinical supervisor ensured that the data collection procedures were followed according to the

ethical review and was available to address any ethical concerns that the participants may have.

A reflexive journal was also used for bracketing and noting down any thoughts and issues that the researcher encountered when carrying out the research. The initial recruitment process was difficult due to a lack of awareness of the study as MHPs did not share information about the study with the FCs. The researcher was not affiliated with the hospital which made it more difficult to recruit the participants. Four FCs declined to participate because of a lack of time or rapport with the researcher. Some of them felt that sharing their experiences would not make any significant changes in service delivery. Changes in the process were made which improved the rate of recruitment. A process of building rapport with the participants was introduced prior to recruitment, engaging them over two sessions through phone calls or face-to-face meetings prior to the interviews which helped them to feel comfortable and more willing to participate in the study. During the interviews, some of the participants were observed teary when describing their experiences while others were slightly agitated when expressing their frustrations or challenges that they encountered. The participants were generally forthcoming and hoped that their experiences would help in policy making and service improvements. The researcher also talked with the participants' family members briefly to have a better understanding of the issues that the participants shared during the interview. More information about the researcher's reflections are described in the Appendix 26.

Results

Findings from the individual interviews indicate four main themes with a number of sub-themes. Table 6.4 shows the list of main themes, sub-themes of and the number of representations in each sub-theme. The quotes were taken from participants and italicised to illustrate the themes with clarity.

Table 6.4: Master themes, sub themes and the participants that contributed to each sub theme

Master themes	Sub themes	Participants contributing to the themes
1. Making sense of behaviour	i. Not easy to take care of someone with behavioural problems	1, 2, 3, 7, 8, 9
	ii. *"We have no choice"*	1, 2, 4, 5, 6, 7, 8, 9
	iii. *"This is God's gift"*	1, 2, 3, 4, 6
2. Some services are better than others	i. Staff need knowledge, skills and a warm heart	1, 2, 4, 6, 7, 8, 9
	ii. Bio-medical treatment approach	2, 3, 4, 5, 6, 7, 8, 9
3. Public reaction - *"If they make a noise, people are scared"*		1, 2, 3, 4, 5, 6, 7, 8
4. Worries and hopes for the future	i. *"What will happen to him when we pass on?"*	1, 2, 3, 4, 6, 8, 9
	ii. *"I want my son to be independent"*	1, 2, 3, 5, 6, 7, 9

Master Theme 1: Making sense of behaviour

The master theme highlights how the FCs tried to make sense and understand the MH and/or behavioural problems of their relative which includes describing the challenges they encounter with them. The theme also describes how the behavioural and/or MH problems have affected the lives of FCs and other family members. The FCs also talked about what led them to seek external help in addressing their relative's MH and/or behavioural problems.

Sub-theme 1: Not easy to take care of someone with behavioural problems

The majority of the FCs lamented the changes in their relative's behaviours as they grew older and shared that it was easier to take care of them before they exhibited challenging behaviours. Some of the FCs made a laundry list of behavioural problems that their relative exhibited in an attempt to make sense and understand them while others had more knowledge of the causes of the problems,

> *"Actually, the problem is she will always cry, make sounds when she's alone… All the behaviours seem to change. The problem is she likes to buy things when she is outside, e.g. toys, food but she didn't eat. When I tried to remove them, she would cry and cry for two or three hours non-stop… very difficult to understand her." – FC 2*

> *"There were many changes at home. The first change was that he cannot see different people. It means that his first teacher was a Filipino guy, suddenly another teacher came in and he couldn't take it. Because he couldn't overcome the changes. That's why I came to know he cannot take changes. That's how the picture started." – FC 4*

Almost all the FCs said they felt lost trying to manage the behaviours on their own, and were at times physically assaulted by their relatives,

"Last year in June because I really didn't know what to do and I got hammering from him. He whacked me all the time. So I don't know what to do." – FC 9

In addition, this FC shared that her life changed significantly following the onset of her relative's behavioural problems and became tearful when she recounted her experiences,

"I just went through a divorce last year, so finances are very tight for me. So it's not easy, really I need to work, I need to…and he also has to behave if not the helper will run away. It's a lot of things to consider and me being a single parent, it's not easy." – FC 9

Some of the FCs felt frustrated trying to deal with the behaviours, externalising the behaviours as a 'problem' and finding ways to 'fix' and change their relative,

"Her behaviour is the problem." – FC 2

"Very frustrating. Because you scold her also no use. How you control also… when you look at the way she does things, you'll get fed up." – FC 7

Sub theme 2: "We don't have a choice"

Most FCs admitted that seeking professional help was the last resort and made the decision when their relative exhibited severe behavioural problems,

"She became violent, she hits people, she hits her teachers, she screamed and has some obsessive behaviours like washing her hands. She even acted up in church. She was screaming and throwing chairs. We had to carry her out during the worship. So that's when we started bringing her to hospital." - FC 1

Some of the FCs decided to seek specialist treatment when they did not see any improvement in their relative's behaviours after engaging with mainstream services. Two

FCs recounted that her adult son had repeated hospital admissions whilst receiving mainstream services, with no significant improvement in his behaviours,

"I felt it was getting worse, and there was no improvement, and he was always sleeping all the time." – FC 4

"I brought him back, it's on and off…he's okay then I take him back for home leave for two weeks, but then he will return to hospital after a few days." – FC 9

Some FCs reported that police were called to deal with their relative's behaviours which resulted in their FC being forcibly admitted to the hospital for treatment. They described that they were unable to object to admission for mandatory treatment,

"A member of public called the police when my child was outside of the house. So my child was locked here in hospital for about one week." – FC 5

The use of restrictive practices such as restraints was viewed acceptable by FCs once their relatives were admitted to hospital for treatment. They rationalised that their relative had become too violent or aggressive for the hospital staff to handle them, *"They would tie him up which is ok with me because he gets violent" (FC 9).* In fact, some of them viewed restraints as a form of punishment when their relatives did something wrong and viewed it as part of the treatment process,

"He said he was tied up. But I think he must have shouted very loudly and refused to sleep, he should not complain, he must have done something wrong." – FC 3

"Normally, I know she sulk (anger outbursts) they tie her in hospital. When she's at home, we cannot tie, it is wrong. They can tie because she is strong you know. Cos this is hospital, they have the right to do." – FC 2

Sub theme 3: "This is God's gift"

When discussing the challenges and difficulties in managing the behavioural problems of their relatives, FC talked about their caregiving roles and acceptance of their relative's MH problems. Some attributed their caregiving responsibilities to their own religious views, seeking comfort from their religion while doing the best they can,

"I accept him for what he is, for what God gave me. I really appreciate that. This is God gift. I just take care as I can." – FC 4

Others emphasised their relationship bonds with their relative such as parent-child relationship which kept them going and prioritised their child's emotional needs over themselves,

"This is my responsibility, have to take care of her because she is my daughter. Sometimes I do feel angry but for me this is normal. I will sayang (comfort) her because she's my daughter, just take care of her." – FC 2

FCs viewed themselves as advocates for their relatives when navigating the community and general health services and discussing treatment options with SMHPs, making efforts to ensure that their relatives could have access to community services and addressing any misconceptions regarding their relatives,

"They (support staff) called me and brought this (sexualised behaviours) up as a big issue, they call me up and all that. I wasn't very happy and I felt that they were being very rigid…I want him to go somewhere to learn something and to expose him to things in the outside world." – FC 6

Feelings of sadness and anger were associated with their role as caregivers because the FCs had been taking care of their relatives for many years under stressful conditions. FCs had

learnt to cope with their feelings by focusing on having unconditioned love for their relatives and were resigned that there was no one else available to take care of them,

> *"Actually, feeling sad until I'm used to it. This is how it is. Must love him. If you don't love him, how are you able to handle (his behaviours). Have to take care of him after he's born. Sometimes you have to explain to yourself. If you don't take care of him, who will do it for you?" – FC 3*

Indeed, one FC identified unconditioned love for their relative as the reason for putting their personal needs aside and giving up their job,

> *"I sent back my helper. I resigned from work I told her (work supervisor) no point because between family and work, I would choose family." – FC 4*

When talking about their role as primary caregiver, FCs often engaged in humour and laughed at times during the interview to provide moments of levity when describing the challenges and burdens they endured,

> *"Then she asked why they (doctors) want to come to question me. I told her maybe to interview me about my mental or medical condition? She said why the doctor wants to interview you, I said they want to check me and maybe want to send me to hospital, then you stay at home. Hahaha (laughs)." – FC 2*

Some of them identified positive aspects of caregiving that included identifying strengths of their FCs and their improvement following specialist treatment. They shared that knowing these aspects helped them to continue with their roles despite the struggles they faced, *"There's pain but I just enjoy the pain as well. In the end I'll be happy providing a service for him." (FC 4),*

> *"If there's something that he wants and we are not able to get immediately, so I told him I'll get it at the end of the year for his birthday.*

It's ok. However, one thing is he'll ask everyday but he won't throw tantrum." – FC 6

Some FCs hoped that more could be done to alleviate their care burden from time to time. For example, two FCs reported that having increased accessibility to respite care services would be helpful as they could take a break or attend to their personal needs such as attending their medical appointments,

"That is also something that I would like to have, you know? Somewhere where I can go for a week or two for a break. Respite. Yeah respite care will be good." – FC 9

"That day I went for medical check-up last month, that's why I asked the social worker to put my daughter there (in the hospital) for a few days. I also have a lot of appointments, no choice…" – FC 2

Having a support group for FCs is something that FCs found useful so they could learn and find emotional support by sharing and talking with other FCs with similar experiences,

"If you have anything, if you want to talk to anyone on anything, they will talk to you. Then when we learn the course, at least we know all sorts of different cases and how we should treat people." – FC 7

"We have a parent support group, so I joined in some of the activities. She was in the bowling team and art and craft. Sometimes there's activities for both of us together." – FC 1

Master theme 2: Some services are better than others

This theme describes the evaluation of specialist MH ID service from the perspectives of FCs and identifies desirable qualities that they would like SMHPs to possess. FCs also described their experiences of interacting with SMHPs.

Sub-theme 1: Staff need knowledge, skills and a warm heart

There was a consensus among the FCs that SMHPs were seen as *'experts'* to provide guidance and advice on how to deal with the behavioural problems of their relatives, *"Because we don't have the expertise, and they go for training, research and all that, they should know better. They are the ones who should advise us." (FC 6).* FCs contrasted healthcare staff in mainstream and specialist services, stating that mainstream staff were ill-equipped and fearful of their relative,

> *"They tied him and brought him to hospital. At polyclinic, they called the ambulance because they said that this boy was very violent. Even the doctor was so scared I had to ask him if he was ok." – FC 4*

One FC reported a lack of empathy in mainstream staff when her request to transfer her child's treatment to specialist MH ID service was repeatedly denied,

> *"They (mainstream staff) didn't tell me how severe but they did tell me that he's very well behaved in the ward and very calm. So they said "why should they send him to specialist service?". But I said "then he has to improve". You cannot send him back and then I return him back (to the hospital) because his behaviour is horrible." – FC 9*

The strong deference to authority and respect for SMHPs suggest that FCs prefer a '*top-down'* approach where SMHPs have the solutions to '*fix'* the healthcare issues of their relatives, such as taking blood or X-ray tests,

> *"I hope they can do the blood test, but they must know the situation, they cannot just ask him to sit down and take. That one, the hospital or doctor must arrange to do that, because they cannot ask us, so what you want to do? How you want to do the blood test? I have no idea how to do but I know he cannot sit down and do. The needle cannot poke in, he will shake. So the doctor must come out..." – FC 8*

When contrasted with mainstream staff, FCs reported a higher satisfaction with specialist services and staff, *"I'm happy with that service. The way the doctor talked to him and talked to me, I was very happy with the service" (FC 6).* They noted that SMHPs are more patient with appropriate skills to communicate with their relatives. FCs felt surprised when their relatives engage positively with the SMHPs. They theorised it is likely that SMHPs are *"able to control your (their) emotions"* and *"have a heart to love to work with this people" (FC 2),*

"Sometimes when she (family member) goes, she's very happy. She would call the doctor's name excitedly." – FC 7

"The doctor knows how to handle; he just remains calm and quiet. He would tell my son to sit down and he would sit down. I think my son knows already; this doctor cannot play." – FC 4

Patience was identified as the most desirable quality in SMHPs because they felt that this was most important when interacting with their relatives, taking sufficient time to know them and treating them as adults, *"They treat her normally. I guess they are more patient. They will talk to her nicely." (FC 1).* Additionally, FCs perceived that having knowledge and patience makes a difference in how SMHPs treat them and their relatives, taking time to prepare materials to help them understand the condition of their relatives better,

"Professional staff understands this type of people so they treat them with care and more sensitive towards them. Whereas the public don't care." – FC 7

"Both my son and I don't know so they are always ready with their own handouts, prepare notes, and tell me what to do." – FC 6

Sub-theme 2: A bio-medical treatment approach

Majority of FCs associated the specialist services with a bio-medical model of treatment often including the prescription of antipsychotics (such as Risperidone or Haloperidol) by medical staff. Some of them were initially against using medication and believed in using religious practices as a way to address the MH symptoms, *"I even brought him to the temple and we did prayers for him and all that because we believe that. But it still continued" (FC 6).* FCs consulted medical staff for prescription of medication which was viewed as a way to *'control'* the MH problems, *"depress his anger, mood swings" (FC 9),*

> *"Actually, for so long I didn't want to put him on medication but as he grew older, he became stronger, I couldn't control him so in the end I had to succumb all the medication." – FC 9*

FCs became familiarised with the bio-medical model of care and did not question the medical staff even when they did not receive adequate information about the rationale for using medication, *"Because at the outpatient, the doctor didn't explain much. Said that just give her medication. Yeah I don't think I really have an explanation" (FC 1).* In contrast, another FC felt helpless and viewed his child as an *'experimental subject'* for medical staff,

> *"There's very little explanation, no need to explain, just adjust dosage of medication, want to take more or less. Very little changes to medication, just adjustment of dosage to improve his mood. If there are side effects, will change to another type of medication. If the effect of the medication is not good, dosage will be increased. When it's better, dosage will be decreased. So when we bring him here it feels like testing but that's the reality, we have no choice, we know our child is like that." – FC 3*

This left him dissatisfied because the consultation time was too short for medical staff to address his concerns, *"the consultation is very fast. It takes about half a day to come here*

for appointment. But the doctor sees my child for 5-10 mins and prescribes medication. It seems very routine and fast" (FC 3). This was affirmed by another FC who adamantly rejected the bio-medical diagnostic label of their relative and found medication to be unhelpful,

> *"My child just has a bad temper. My child should be with normal children, not special needs children; with normal children, he is able to articulate, but he doesn't want to with special needs children. He was prescribed medication but his father told him not to take the medicine as it causes him to have diarrhoea." – FC 5*

This FC continued to elaborate on receiving little benefits from specialist MH ID service, viewing the consultation as a meaningless routine, *"I mean nothing special. It's the same however way to describe it. We have to come for appointment, cannot don't come" (FC 5).* However, most of the FCs found medication to address behavioural problems helpful despite strong side effects and adjusted the dosage themselves to reduce the side effects,

> *"The doctor suggested me this tablet. I try to adjust it; if I give him two and he feels drowsy, then I minus one, giving him one in the morning and one at night. I estimate by myself. That's when he became better and did more exercises. Taking swimming, making rounds, jogging for 3 rounds, he'll come back." – FC 4*

The side effects of the medication were something that majority of the FCs were concerned about and some of them refused to increase the dosage despite both mainstream and specialist medical advice,

> *"Then they (mainstream medical staff) ask me how he is, ask me if he makes noise and all that. If they want to increase the medicine, I don't want to increase the medicine because the medicine got the side effects. So I say don't want to increase I can manage. Then after they recommend*

me the specialist doctor, he also sometimes ask me, then I ask him, you want to increase the medicine, he said can increase but got the side effects. So then I say never mind, I try to manage this dose." – FC 8

Other side effects mentioned were obesity and early onset of diabetes,

"He gained weight as a side effect due to the medicines. Every 3mths of appointment, he will gain 5-8kg, and it is very high and he also developed diabetes. So I follow what the doctor suggested to go for more exercise. Because his weight goes up very fast and the doctor told me it is not good for his health. Actually they are very concerned about the heart." – FC 4

FCs weighed up the pros and cons and continued with the medication despite their own reluctance as they noticed an improvement in their relative,

"So mine became worse when he became older but now with all the medication, he's much better now. But now he's on much more medication than he was before. So what to do?" – FC 9

FCs reported that, unlike MMHPs, SMHPs made efforts to recommend non-pharmacological approaches provided by allied health services including occupational therapy and psychological services, which they found helpful,

"Previously I saw just a normal psychiatric doctor, they don't know anything about autism. Just only for the medicine case. The specialist doctor takes over him, he recommends psychologist and occupational therapist. Their service is very good. Very, very, very good. The way she is telling him, he also can do work with the people. She also doing well, he also doing well with her. So she tell me what to do, she teach me what to do and I follow the things at home." – FC 8

Master theme 3: Public reaction - "If they make a noise, people are scared"

This theme describes the FC's perceived public reaction towards their relative with ID and MH problems and the adjustments they made to cope with dealing with this. The majority of them found that their neighbours and people living in their neighbourhood were supportive and understanding, especially when their relatives made disruptive noises and they checked upon them to ensure safety, *"Most of my neighbours here understand. Last time when he starts to bang on things, my neighbour will come and ask what happened, whether there was a fight. I will say no, my son angry so he's hitting things. Because what happens here can be heard next door; so they know and understand" (FC 4).* Some FCs noted that people in their neighbourhood responded positively towards their relative, *"All the outside people in my neighbourhood where I go, my friends, everybody's response to her is good. All the people in the market know her" (FC 2).*

One carer noted improvements in public reaction compared to the past when their relative was younger,

> *"It's better now. Won't have negative reactions to those like my child when he was younger. Last time I think people are scared of this type of children but now the mindset is different." – FC 3*

On the other hand, another FC recounted her adult son's experience of being bullied,

> *"Many people judge from his appearance that he is a special needs child. So they like to bully him. He told me a man saw him and used a rubber band trying to hit him. If I had witnessed, I would scold this person. Why would you do this when he did not do anything to you?" – FC 5*

Some FCs accessed public transport services with their relative with varying success. One noticed that the public would offer them seats, *"They are actually quite kind. They will give us seats in the train or bus" (FC 1).*

Most of them noted that the public would focus on their relative's disability, *"Only if you go to other places that are not familiar, and she starts sulking. Then people see... After a few minutes, people will realise oh this one is not normal" (FC 2).* Some of FCs noted a change in reaction when their relatives attempted to express themselves verbally which attracted curiosity and questions from the public,

> *"Because appearance if you saw him right, even at the hospital, people won't say that he's special. But when he opens his mouth and talks to me then people stare. Cos the way he speaks is different; like a child, he'll speak. Even when we go into the cab, the taxi driver will know and ask whether my son is special." – FC 6*

There are various ways that FCs reported they dealt with public reaction. Some of them preferred to act and treat their relative normally, *"I feel if I had accepted her, treat her as normally, others around when they see it, they will also respond the same" (FC 1),* while others provided short responses to increase the public understanding,

> *"They will ask why like that; what happened. I will say auntie he has low IQ. Response is oh like that; they will say different things. I will just reply yeah; make sure they know, then is ok." – FC 4*

One of the FCs nonchalantly ignored public reactions when she took her son out, *"I don't know. Never notice my surroundings (laughs). I am so used to it, I don't bother. All these years of him growing up, I don't bother what people see and what people says. I don't care" (FC 9)* whereas another FC chose not to allow their son to take public transportation,

keeping them at home and out of sight to avoid negative public reactions. This particular FC specifically highlighted her feelings of embarrassment should her son becomes aggressive and difficult to manage as she felt that people may react negatively,

> *"Cannot bring him out in the public, bus, because he will be frustrated, he shout. You know most Singaporeans, still they got a lot of things but they still "Woah, what happened? What's that?" We also feel very embarrassed. So we also feel very embarrassed. So I don't want to…mostly we won't bring him out to crowded areas. Because he is already grown up, tall and all that. If make noise, people scared. Maybe he will harm them or something." – FC 8*

Some FCs felt resigned that their relatives would be excluded from the society as employers are unwilling to make efforts to employ them,

> *"I think Singapore system is such that you are… they want perfection and I don't think they have the patience to employ such a person…" – FC 1*

Most of their relatives were attending some form of supported training at specialist job agencies. However, a few participants reported that the services were suspended or cancelled as the job trainers did not allow their relative to return after receiving specialist MH services, which left them feeling disappointed,

> *"I can talk to the centre and ask them to assign him a male coach like before and we see how things go. They said I should be ok and asked me to hold. Then I was waiting and waiting till February and nothing happened; I was thinking why nothing happened and nobody called." – FC 6*

Master theme 4: Worries and hopes for the future

This theme describes the uncertainty that FCs face when they think about their relative's future, specifically their concerns regarding the continuity of care. FCs described their hopes and wishes for their relatives, as well as their views on how specialist services can help to address their concerns.

Sub theme: "What will happen to him when we pass on?"

Almost all the FCs raised concerns regarding the continuity of care after they were no longer around to provide care for their relative. Three of them expressed preference for their relative's siblings to look after them though expressed uncertainty whether they were willing to take up this huge responsibility and burden, *"Hope that her brothers will treat her well. That they will still care for her…" (FC 1).* One FC cited an unwillingness to trust professional staff, *"Outsiders, they are not very trustable. Maybe because they go for money and all. So their sisters definitely will take care of him and handle everything" (FC 8).* Two of the FCs stated that they preferred professional staff to look after their relative as they do not wish to transfer the care burden to their relatives or were uncertain whether they would take the care responsibilities seriously,

"I don't want to burden anybody, let me carry my own burden." – FC 4

"I want professional staff. Family changes. They are good this year but the next few years down the road... family change, people change. I rather have a professional body looking after his personal things, his needs and all that." – FC 9

Only a minority of FCs had made substantial plans to ensure that their relative with ID would be taken care of when they were no longer around. One of them stated that she informed her relatives and made necessary arrangements in finding a suitable residential institution.

Some were not ready and reported that they had not started any plans, citing bureaucracy and high costs as reasons for not going through with this process. One FC felt that it was *"pointless to keep thinking and worrying about this, we just comfort ourselves by telling ourselves that we leave it to God" (FC 3),*

> *"There is a lot of red tape, a lot of costs. Because to go through a lawyer, you need costs, get a medical record also a cost." – FC 1*

> *"I really don't know because now there is the trust fund which they started ten twelve years ago which was so damn expensive that I did not want to sign up. Now it looks like it is more sustainable. So I'm thinking about it." – FC 9*

One FC found it difficult to arrange future care plans because he was worried about his own medical problems,

> *"I don't know. I have no idea. I still hope but don't know whether she can change her behaviour. Because sometimes I also think if I cannot walk, cannot do anything, then how? I also don't know how to take care of her. Because last time I had an operation and it became a problem taking care of her. Now I still have pain but can walk with my stick. That's why I know already if I cannot walk, I also don't know how to take care of her. It is very very troublesome." – FC 2*

Despite the uncertainty about future care plans, all FCs reported being protective towards their relatives as they wanted to continue taking care of them for as long as they could and saw no reason for professional staff to take over while they were still around, *"As long as I'm around, he's not going anywhere. He is going to be with me" (FC 9).* They strongly rejected the idea of putting their relative in a residential institution because of strong cultural views and a sense of identity as a parent carer,

"Children will let their parents go to a residential home because their parents are old and they have their own commitments; but mothers won't do that." – *FC 4*

Sub theme: "I want my son to be independent"

When reporting on their worries and concerns regarding uncertainty of their relative's future, the FCs also reported feeling hopeful and expressed a desire for their relative to become more independent. Three FCs reported that their vision of their relative being independent was to be able to *"find a job, spend his time and make friends" (FC 5).* One of them expressed the hope that his child could find work so as to improve his self-esteem,

"Because I think his behaviour and self-esteem will improve if he has a job and see himself working – "I can work". Sometimes he will tell me "I don't have a job, others are working, why am I not working?" – FC 3

FCs taking care of relatives with more severe conditions, on the other hand, expressed uncertainty regarding their relative being able to take care of themselves when they were no longer around, *"I don't know (laughs). That he would be independent... I doubt so. Independence as in he can go on his own to do stuff" (FC 9).* Some of them reported that they would be satisfied and happy for their relative to perform basic activities of daily living[3] (ADL) tasks*, "Be independent, go toilet shower himself, eat himself, now all these things now we are helping. He needs the help. So I just hope he can do it by himself. That is the only thing I need." (FC 8)* whereas others expressed caution and some pessimism,

[3] Activities of daily living are basic tasks of daily life activities that most people are able to perform without assistance. The ability to perform these activities can determine medical status for health coverage and long-term care decisions of the person.

"I want my son to be independent, that he can bathe himself. But I'm still trying with him, I know that he can't. I don't want to hope anything." – FC 4

Using public transport independently was also something FCs yearned for their relative because of better opportunities available for them. One FC expressed concern about letting her son travel independently, *"I don't have the confidence to let him because we never know what may happen" (FC 6)* but expressed optimism for her son to reach that goal someday,

"The next thing I want for him to do is to travel independently. I want that independence for him because I feel that once he can do that, it will boost his confidence more. I feel that he lacks confidence. Once he's trained to do it and he confidently does it by himself, I think that it will do something good for him. I have a feeling. Then maybe if given a chance and he can go for an employment, I will be very happy." – FC 6

FCs discussed about how governmental policies could be adapted or further developed to help their relatives become more independent. One FC called for the government to allow male support care staff because of the high ratio of males being diagnosed with ID and MH problems requiring care,

"But in Singapore they don't allow male domestic worker (support worker). Only female. If male, he is very free, he can shower him, whatever he wants, he can. But female is difficult… You all can help to ask the government to do is better. Like this type of children mostly are boys. Male domestic helper is better." – FC 8

Other FCs called for increased accessibility of mainstream services for their relatives with ID where they can participate in activities and exercise in the community. Some would like to have more financial support to access community services and carers allowance as they did not have available time to work due to their care responsibilities,

"Some sort of activities, even art and craft or swimming. Other activities which they have for senior citizens or for children. All those can also be done for the disabled. Of course I know this means they will need people to take care too and the space… Exercise also. They can do some sort of exercise programmes for the disabled. Because I heard that there is a gym clinic for those 55 and above, they teach them how to use the gym machines. Such can also be done for the disabled. Because they will also need some sort of exercise or some therapy." – FC 1

"When you take care of this type of person and you cannot work, you cannot do things or earn money, there's a problem and it is very difficult." – FC 2

Lastly, one FC felt that the government should promote more awareness amongst FCs to seek help despite the stigma. She perceived that there might be other FCs holding negative attitudes towards their relatives as a result of poor knowledge and education and as such were not willing to seek appropriate help and instead hid their relatives away from the community,

"It is not those uneducated who will think that they are crazy and there is nothing you can do about it. At least when you're educated, you know where and when to seek for help and you must be outgoing. You mustn't be shy. Don't feel that this is a stigma or shame. If you cage yourself and don't approach people, how would people know what sort of help do you need? The more you cage yourself, the worse it is." – FC 7

Discussion

This study intended to explore the experiences of FCs caring for their relatives with ID and co-morbid MH problems in Singapore, how they view the specialist MH ID service for their adult relative and the impact of care burden on them and their family. IPA was used to analyse the individual interviews which found four major themes: 1) Making sense of behaviour, 2) Some services are better than others, 3) Public reaction and 4) Worries and hopes for the future.

The findings of this study fall in line with the universal trend that FCs encounter difficulties in taking care of their relative with ID, especially in identifying and managing their challenging behaviours. These difficulties contribute to significant stresses in their lives and affect their emotional well-being (Dawson et al., 2016; Kim, 2017; Kim et al., 2003; Maes et al., 2003). Irazabal et al. (2016) found feelings of grief, anxiety and sadness among FCs when they became aware of their relative's MH and ID diagnoses. Another study has highlighted the confusion that FCs experience when trying to understand the behaviours of their relatives and feelings of helplessness when attempting to deal with them (Faust & Scior, 2008). The behaviours of their relatives are said to control their lives and result in anxiety and depression (Waite et al., 2017), suggesting that FCs' perception of their relatives' behaviours has a significant impact on their lives and many describe the personal sacrifices that they have to make when taking care of their relatives.

The FCs in the current study did not seek early treatment to deal with their relative's behaviours and waited until it became overwhelming for them. While all of them ended up using the specialist MH ID service, some of their relatives received MH treatment as a result of being referred by the police. An possible explanation is that FCs lack knowledge to

identify the MH problems in their relative and attribute their behaviours to their diagnosis of ID (Faust & Scior, 2008), which is commonly known as 'diagnostic overshadowing' (Jopp & Keys, 2001) and also commonly occurs among HCPs working with this population (Mason & Scior, 2004). Past research findings indicate that FCs who lack awareness of MH conditions in their children with ID often deny the severity of the issues despite noticing initial signs of behavioural problems (Yoo et al., 2018).

FCs in the current study were more likely to focus on the relationship and bond with their relative when describing how they deal with their caregiving stress and responsibilities, for example they spoke about who their relative was and what they meant to them within their own cultural context in Singapore. Research has found that FCs in western society use similar approaches (Dunn et al., 2020), although other researchers have shown that mothers in western society adopt problem-focused and emotion-focused coping strategies (Kim et al., 2003; Redmond & Richardson, 2003). FCs using the relational coping strategy seek to re-interpret positive aspects of their relationship with their relative as a way of accepting their relative's disability and re-interpreting their caregiving responsibilities (Lam & Mackenzie, 2002; Mak & Ho, 2007; Wang et al., 2011). This may provide possible explanations regarding why they did not give up their care responsibilities despite encountering high levels of stress and challenges. Another possible explanation is that the FCs may likely endorse collectivist values that focus on needs and interdependency within families. Hence they considered their relative with ID dependent on them to take care of them and as such, FCs may choose to place their negative feelings aside and not dwell on them too much (Kee, 2004). The FCs in this study struggled to understand the behaviours of their relative while at the same time dealing with their own feelings of sadness, anger and grief, yet they chose not to pay attention to them and developed positive reinterpretations of their current situation, a

coping strategy also observed by Wang et al. (2011). These authors found that carers used various strategies by which to recognise positive aspects of caregiving instead of dwelling too much on the challenges. However, there needs to be further research to examine whether the use of different coping strategies can be attributed to divergent cultural values and beliefs in FCs as there are other factors that could explain for these differences in how they cope with their caregiving demands and stress. For example, the accessibility and quality of services provided to people with ID differs between each countries which could influence how FCs adopt coping strategies in dealing with their relative's MH problems and the challenges they encounter when managing their challenging behaviours.

Some FCs in this study attempted to make sense of their caregiving responsibilities by means of a religious perspective. Although they experienced feelings of sadness and anger as an emotional response to the high stress and challenges in taking care of their relative, most of them spoke positively of their role with some describing their child as "God's gift", similar to Gabel (2004) findings reported in a study conducted in a South Asian Indian culture. While disability of the person is sometimes regarded as a punishment from heaven by western FCs (Bhaumik et al., 2018), non-western cultures may view the disability as a test of their religious faith and accept the caregiving role as divine fate (Heer et al., 2012). The use of religion helps FCs to interpret their relative's disability in a positive light and facilitates the acceptance process despite the social stigma as well as physical and psychological challenges of taking care of them (Crabtree, 2007). Heer et al. (2012) propose an experiential-contextual framework of disability to explain how families create personal meanings shaped by their own culture, religion and ethnicity to make sense of the disability of their relative while integrating the bio-medical information of the disability and the social attitudes of the society that they live in. The role of family resilience also influences how

families accept the disability of their relative and the impact on their relationship with this relative (Duca, 2015). The FCs in the present study appear to have come to terms with the challenges associated with taking care of their adult relatives, unlike western carers who reportedly struggle to accept their child's disability and behavioural problems (Sin et al., 2010; Van Wyk & Leech, 2016).

The findings of this study suggest that FCs are satisfied with SMHPs and view them having a better understanding of their relatives than they themselves or MMHPs. They perceived the latter as ill-equipped and fearful of working with their relative. As such, FCs showed a willingness to defer treatment decisions to SMHPs and did not raise objections even when restraint was used to manage their relatives. Foo et al. (2006) argue that the HCPs in Singapore are perceived as 'experts', leaders with an authority with the public respecting their profession and knowledge. Understanding this cultural tendency may explain the reasons why FCs did not raise objections to the use of restraints as they viewed MHPs acting in good faith to ensure their relatives' safety and protect them from harm (Zwijsen et al., 2011). Another possible explanation is that SMHPs took time and effort to develop trusting relationships with FCs and their relatives in contrast to UK research findings that indicate a poor level of trust and poor collaboration between FCs and SMHPs (Scior & Longo, 2005; Wodehouse & McGill, 2009). FCs in this study reported to have established good working relationships with SMHPs over time through observing how they interact with their relative during consultation services, acknowledging that the SMHPs have the desirable quality of patience and the necessary skills to interact and communicate with people with ID (Stringer et al., 2018).

In the subtheme *"A bio-medical treatment approach",* FCs reported a strong preference for the use of medication as a treatment for MH problems. Although there is an emerging trend of considering a biopsychosocial model for the management of people with MH problems in Singapore, there is still a lack of awareness among FCs and some HCPs of this model and of non-pharmacological approaches (Parker, 2000). Non-pharmacological therapies were very much considered as adjunct treatments that complement the biomedical model by both FCs and MHPs. Unlike the UK findings that revealed negative attitudes by FCs towards medication (Rasaratnam et al., 2004), FCs in this study reported favourable outcomes for the use of medication and ensured that their relatives complied with the prescriptions.

This is not to say that FCs were satisfied with the continued use of medication in the long term as they raised concerns about side effects such as obesity and diabetes, and some titrated the dosage on their own to minimise the side effects. FCs in this study were not provided with adequate information regarding the duration of the use of medication and SMHPs did not appear to be working with them towards reducing the number of medication. Stenfert Kroese and Holmes (2005) recommend that non-pharmacological treatments, such as FBA, should be carried out initially to identify the root causes of behavioural problems and environmental changes in the setting before using medication for challenging behaviours. More recently, the STOMP initiative in the UK is a national project that addresses the overuse of psychotropic medication and encourages HCPs, FCs and support workers to consider alternative non-pharmacological approaches to address challenging behaviours (National Health Service England, 2016). A review (Branford et al., 2019) found a high proportion of people with ID and/or ASD in the UK and the UK are taking psychotropic medication without the presence of severe MH problems. Several national initiatives have

been carried to address this issue such as providing resources for FCs to increase their awareness and help them discuss medication with their relative's HCP (Branford et al., 2019).

It appears that FCs in this study were unaware of the causes of their relative's distress and viewed the use of medication as a way to control the symptoms rather than seeking to understand them better, which was reinforced by MHPs' willingness to increase the dosage despite the strong side effects. Some FCs were initially apprehensive and uneasy about the prescription of medication and lacked knowledge about the non-pharmacological interventions to address the behaviours. Sheehan et al. (2019) identified an imbalance of power dynamics between medical staff and FCs where the FCs often acquiesced to the doctor's decision for their relatives to take psychotropic medication without any discussion. FCs in the study noted the lack of knowledge among MMHPs of non-pharmacological approaches and were pleasantly surprised with the improvements in their relative after the SMHPs referred them for non-pharmacological interventions. This suggests the clinical importance for MHPs to improve communication between FCs regarding the use of medication (Sheehan et al., 2018), developing a health plan with FCs to identify the causes of the behavioural or MH symptoms and using non-pharmacological methods such as FBA and PBS as the preferred choice.

Being out in the public with their relatives with ID meant that FCs in the study had to deal with public scrutiny and reactions. Similar findings across South Asian and Eastern cultures indicate that family members are worried about their social image and fear that their relatives disrupt public norms (Heer et al., 2015; Yang, 2015). FCs noted that the Singapore public is sometimes benevolent and tolerating towards people with ID who are often regarded with curiosity and scrutinised in public. FCs in the UK also reported to feel

scrutinised and having to disclose their relative's diagnosis (Ryan, 2005). Unlike research findings that highlight a reluctance of carers to bring their young children with disabilities out in public (Crabtree, 2007; Lam & Mackenzie, 2002), some FCs in this study demonstrated a willingness to bring their family members out and have developed strategies to deal with public reaction. This difference may be due to age-related factors as the FCs in the current study are significantly older and are probably more confident and have had more time to get used to the public's reaction and scrutiny. Similarly, the neighbours of the FCs in their close communities may have grown accustomed with their relatives, confirming the evidence found in literature that contact exposure is one of the factors that influences public awareness and attitudes (Scior, 2011). However, some FCs did not let their relative with ID to access public services and instead isolated them at home which may indicate that public acceptance and inclusion in the community for people with ID require yet more time and effort to reduce public stigma and prejudice.

Employment opportunities for people with ID were strongly emphasised by FCs. There is a strong work culture in Singapore and a desire for people to be seen as productive and contributing towards the economy (Leong et al., 2013). Singapore has no natural resources and is dependent on its citizens to contribute towards economic progress, adopting a meritocratic system where hard work and ability are rewarded through upward social mobility (Teo, 2019). FCs in this study expressed a hope that their relatives with ID would have some form of employment as a way of promoting their independence and integration in society. This strong emphasis towards employment is shared by most of social services in Singapore for people with ID which aim for their clients to receive job training and gain either open or supported employment (Cherian, 2002). Thus, these results may suggest that FCs in Singapore are exposed to the unique culture and societal norms regarding

employment and as such are reflecting on how their relatives are excluded from society. Research has suggested a strong association between employment and better physical and MH outcomes for people with ID (Robertson et al., 2019) which FCs appear to strongly believe that having some form of work would benefit their relatives' self-esteem and increase their confidence to take care of themselves independently.

There are concerns among FCs regarding how their relatives would be cared for after they are no longer around. The majority of the FCs in this study are above 60 years old and Singapore has one of the highest proportions of ageing population in South East Asia (Department of Statistics, 2019) which suggest a need for ID disability services to include future care planning for elderly caregivers. A review (Ryan et al., 2014) highlights that ageing FCs found it difficult to give up their caregiver role despite poor health and did not have available services to address the future planning issues. The issue of future care planning is a concern among FCs in Singapore as highlighted in a news article (Phua, 2019) in which financial worries and worries about poor coping by their relatives with ID after they are no longer around are expressed. This concern regarding future care planning is recognised by the Singapore social policy document entitled *Enabling Masterplan* (Singapore Ministry of Community Development, 2016) which recommends setting up services to address the issues related to care planning in FCs. FCs in the current study identified strongly with their caregiver role and had not given much thought to making future care plans (McEvoy et al., 2012). FCs may face difficulties transitioning their caregiving responsibilities in the future and more support is required from the specialist MH ID service to provide psychological support to the person with ID when their FCs are no longer around.

The FCs in this study had different expectations of the future care of their relatives. Most did not think that their relatives were able to live independently and instead focused on other family members taking care of them. There was some resistance towards placing their relative in an institutionalised setting due to a lack of trust in support staff. However, Singapore only provides large residential dormitory settings where people with ID are cared for when their family members are unable to (Ong, 2018) unlike the UK and Australia where there are a variety supported living accommodation arrangements for people with ID (Harvey et al., 2012; Randell & Cumella, 2009). Hamlin and Oakes (2008) argue that institutionalisation for people with ID reinforces the notion that this group is powerless, unable to contribute towards the society, dangerous and in need of protection from the public which may reinforce the biomedical model of care and treatment, viewing symptoms as treatable by medication only and disempowering people with ID by refusing them access to mainstream services and having interactions with the public. The UK, Ireland and Australia have shown some success in deinstitutionalising people with ID by offering various options of supported accommodation according to their needs and level of care required (Emerson & Hatton, 2009; Stancliffe, 2009).

Implications

FCs in the study requested support to help them through the difficult moments when they need some time apart from their relatives. Thus, the need for respite care services is implied as findings indicate that having respite care services can help to offer relief when FCs feel overwhelmed with the high care burden (Irazabal et al., 2016). Psychological distress as a result of high carer stress is reported here as in other research, highlighting the need for services to cater and address the emotional well-being of FCs through support groups or psychological interventions.

There was confusion expressed regarding how to address health issues of their relatives as FCs reported to feel lost and did not know where to seek information. For example, FCs in this study were concerned about obesity and unsure about how to address this issue with their relative's physician. Research has suggested that the design of a health action plan can be a valuable tool to communicate important health-related information to FCs as well as identifying appropriate interventions to target health issues (Howatson, 2005). Developing a user-friendly and easily accessible MH guide for FCs (Gratsa et al., 2007) to provide information about the MH problems of people with ID, where they can seek help and treatment for their relative, and a brief description of the specialist MH ID service in Singapore. Support staff in the community can attend additional resources and training to screen early on-set MH or behavioural problems and work with FCs to provide simple non-pharmacological techniques to identify triggers and de-escalate the behavioural problems or facilitate early access to specialist MH ID service if needed (Bouras et al., 2005).

Current findings also indicate that mainstream services are sometimes ill-equipped to address the health needs of people with ID including carrying out certain health procedures such as taking blood or X-rays. Often there is a lack of consistency in using evidence-based practices to address these issues. Having a liaison nurse trained in the knowledge and behaviours of people with ID may help HCPs and FCs to discuss approaches that are most likely to be effective and do not infringe on the rights of people with ID (MacArthur et al., 2015).

It is important that hospital management identifies factors that promote a safe environment for people with ID when they receive healthcare services regardless of location. FCs spoke of differences in satisfaction with mainstream and specialist services, hence more work is

required to train primary MHPs to ensure that evidence-based practices are used to identify and flag MH needs of people with ID for referral. Additionally, government policy makers should provide support to hospital management in order to make reasonable adjustments for people with ID and their FCs, and to explore other ways that people with ID can seek treatment without the need for institutionalisation. Government policy makers can address alternative housing arrangements for people with ID, such as considering small group community-based housing or supported accommodation which may help to improve the public perception of them.

Conclusions

Overall, this study reveals a unique insight into the experiences of FCs in Singapore caring for relatives with ID. There has been no previous research exploring this phenomenon and it also provides an insight into how Singapore culture influences the way FCs think and feel about the specialist MH ID service and public reactions towards their relatives. FCs are generally satisfied with specialist MH ID service and the use of medication to address MH and/or behavioural problems. However, they expressed concerns about the medication side effects and lack of knowledge among MMHPs in understanding and managing people with ID. The findings highlight the need for MHPs to consider how cultural values and beliefs of FCs can have an impact on how they respond to their relative's MH symptoms. Hence, MHPs should continue to make efforts in communicating with FCs to empower them with knowledge and skills as well as listening to and addressing carers' concerns about the prolonged use of medication.

The next study provides an opportunity to understand more about the SUs with ID and their experiences when receiving inpatient specialist MH ID service.

Chapter 7: Study 4 - What are the experiences of service users receiving inpatient specialist mental health intellectual disability service in Singapore?

Introduction

There have been significant changes in the MH services for people with ID in the UK over the past years. In the past, people with ID and MH problems were deemed to require in-patient hospital admissions where their physical and MH needs were taken care of by MHPs working in the hospitals. This would result in long periods of institutionalisation and separation from their families and community which impacted on accessing mainstream facilities and employment opportunities. In the last few decades, deinstitutionalising this specific population and integrating them in their own communities have been the aim of most western services. Community MH services have been set up to meet the needs of people with ID and early intervention services to identify and treat MH problems before hospitalisation is required (Hemmings et al., 2009). There are successful outcomes in countries like the UK and Australia due to deinstitutionalisation such as better engagement with people with ID during treatment, more contact and time spent with their family and friends as well as increased participation in the community (Emerson & Hatton, 2009; Stancliffe, 2009). A significant cost reduction has been found when people with ID are staying in specialist community-based residential settings as compared to hospitals (Cambridge et al., 2002). Additionally, people with ID who are relocated from institutionalised to specialist community-based environments are found to show increased engagement in meaningful activities, higher levels of self-care skills and lower frequencies of behavioural problems (Golding et al., 2005).

A proportion of people with ID continue to require in-patient admission for treatment and care when their MH and/or behavioural problems become too difficult to manage. Devapriam et al. (2015) noted that people with ID who display risky and self-harm behaviours and serious offences or those who do not respond well to non-pharmacological treatment remain in an institutionalised setting where the hospital provides structured care and security. Findings in Chapter 6 indicated that FCs sought inpatient MH treatment for their relatives when they experienced repeated violent behaviours from them and could not manage their behaviours appropriately.

Historically, people with ID have often been excluded from discussions and decision-making about their own care. Until recently, research was primarily focused on identifying the training needs and attitudes of MHPs as well as understanding the caregiving needs of FCs (Bates et al., 2004; Maes et al., 2003; Ouellette-Kuntz et al., 2003; Redmond & Richardson, 2003). Recent findings indicate that poor knowledge and competency among MHPs, a lack of organisational support to provide training and address manpower resources are predictive factors of abuse and maltreatment of people with ID (Parish, 2011; Plomin & Tozer, 2013). Following the systemic failure to provide appropriate care for people with ID (Dale, 2012), there has been an increasing focus on understanding the experiences of people with ID and MH as well as their views and evaluation of services. A review (Cleaver et al., 2010) of disability-related research studies over a 20-year period reported a high response rate among people with ID, which suggest a keen interest in expressing their views regarding various issues.

Most research on people with ID and their experiences of in-patient psychiatric treatment has been conducted in western countries (Donner et al., 2010; Longo & Scior, 2004; Scior &

Longo, 2005) and has identified themes of disempowerment, lack of meaningful activities and not being informed about treatment options. There is a lack of research that focuses on the views and experiences of adults in ID living in non-western countries. Most non-western research to date has focused on the needs of FCs and how they cope with societal stigma (Chien & Lee, 2013; Chiu et al., 2015; Yang, 2015). With the establishment of specialist MH ID services in Hong Kong and Singapore, more recent research has focussed on understanding the training needs of MHPs and has examined the use of psychotropic medication in people with ID (Kwok et al., 2010; Sajith et al., 2017) with little input and involvement from people with ID.

The experiences of adults with ID in western countries may not apply to those in non-western countries due to cultural differences. A lack of understanding of people with ID's experiences of in-patient services in Singapore constitutes a gap in knowledge that requires to be addressed. It remains unknown how they view the specialist MH ID service since its establishment in 2011 or how they understand and make sense of their MH problems.

The next two studies adopt a phenomenological perspective to understand the experiences of heterogeneous groups of people with ID. Given that this is a relatively new, unexplored research territory, IPA was chosen for both studies because it allows the participants to explore and make sense of their experiences and the services they receive (Smith et al., 2009). Furthermore, the researcher has the flexibility to facilitate participants to develop awareness of their own personal preconceptions through asking about their feelings and cognitive processes, thus focusing on meaning making (Smith et al., 2009). There has been a recent trend to use a phenomenological perspective to explore the experiences of adults with ID in the hospital receiving inpatient MH services (Cookson & Dickson, 2010; Thomson

& Johnson, 2017; Tomlinson & Hewitt, 2018) and a recent review (Rose et al., 2019) confirmed that people with ID are able to engage in IPA.

The study reported in this chapter explores the experiences and understanding of SUs (i.e. adults with ID) in Singapore of their own MH condition and the in-patient treatment they receive, using IPA methodology.

Method

Participants

Participants were recruited from a specialist MH service for adults with ID in a tertiary hospital in Singapore. The inclusion criteria were:

1) Diagnosis of ID
2) Aged 21 or over[4]
3) Diagnosed with a MH problem and receiving specialist MH services (inpatient) for a minimum of 3 months
4) Capacity to consent
5) Ability to participate in semi-structured or focus group interview

The exclusion criteria included the presence of acute levels of distress, risk of harm to self or others and/or active MH symptoms.

Participants were six men with ID aged 22 and 70 years old (median age 53). All the participants were unemployed. Four of them had Chinese ethnicity and the others Malay and Indian respectively. The information regarding participants' diagnoses and MH

[4] The minimum age of consent in Singapore is 21 years old

problems was obtained from their clinical records provided by the clinical supervisor. MH labels included schizophrenia and aggressive behaviours. The length of stay ranged from 2 months and 28 days to 32 months 19 days with the average stay being 15 months. All participants had previous multiple admissions for MH treatment and some were transferred out to other hospitals for general health medical treatment.

Participants in the study were de-identified and referred to by the acronym ISU (Inpatient Service User) with the corresponding numbers allocated in Table 7.1.

Table 7.1: Demographics of Inpatient Service Users

Participant (ISU)	Age range	Gender	Ethnicity	Neurodevelopmental and MH labels	Length of inpatient stay
1	20-25	M	Malay	Moderate level of ID, psychosis inappropriate sexualized behaviours	11 months
2	20-25	M	Chinese	ID, aggressive behaviours	15 months
3	45-50	M	Chinese	Moderate level of ID, ASD, schizophrenia, aggressive behaviours	4 months
4	60-65	M	Chinese	Moderate level of ID, aggressive behaviours	24 months
5	55-60	M	Chinese	Moderate level of ID, schizophrenia	33 months
6	70-75	M	Indian	Moderate level of ID, schizophrenia	3 months

Interview Schedule

A semi-structured interview (Appendix 16) was designed based on resources adapted from Unwin et al. (2016). The resources entitled "Tools for Talking" were developed by Unwin et al. (2016) following collaboration with various ethnic populations with ID in the UK. This set of resources was chosen as the foundation for the development of the interview schedule with additions based on previous research on this specific population as well as a number of discussions with two academic supervisors. The interview schedule was comprised of exploratory activities that facilitated participants to discuss various issues namely 1) their level of satisfaction and support they received from MHPs, 2) identifying important people in their lives and 3) changes they would like to make in their lives. Additionally, participants were asked about their understanding about their own MH conditions and prompted to share their experiences of receiving specialist MH ID service in the hospital as described in Table 7.2. The questions in Table 7.2 were adapted according to the participants' level of understanding during the interviews. The resources taken from the Tools for Talking (Appendix 23) allowed participants to communicate their thoughts and preferences in alternative ways, such as choosing images to ascribe meaning to their experiences and writing short phrases or words during the session. As part of the development of the interview schedule, a focus group comprised of people with ID in the UK was carried out to ensure that they understood the activities and they were asked to provide feedback about the activities (Appendix 17). Minor changes were then made to ensure that it is culturally appropriate within a Singapore context. An example of the activity with OSUs can be found in Appendix 22.

Table 7.2: Interview Schedule of SUs

Example of questions
1. What do you know or understand about your condition?
2. Here's a logo of [hospital's name], can share with me about what it is like?
3. What do you like/do not like about your stay here?
4. What kind of things do you like your healthcare worker to help you with?
5. What do you like/ do not like about your doctor/nurses/healthcare worker?
6. Are there any other things/issues you like to be different?
7. What do you like/do not like about your life?

Procedure

Following ethical approval (Chapter 4, Page 132, Appendices 24 and 25), the clinical supervisor identified potential participants that met the inclusion criteria. Potential participants were approached by the researcher, who provided an invitation letter (Appendix 8) that explained the purpose of the study. Potential participants were given opportunities to ask questions and were allowed no less than 24 hours to make their decision. Potential participants could discuss the study with their family members and contacted the researcher to join the study. They were also given a choice of individual or focus group interviews to help them feel comfortable during the interview process. Prior to

the interview, a simplified information sheet and informed consent form were provided (Appendix 14).

Additional considerations included using basic words with large font size 18, pictures and reading aloud to the participants to ensure that they understood the study. Following that, participants were asked four questions regarding aspects of their involvement and rights as a research participant in the study. They could demonstrate their capacity to understand and take part in the study after answering four questions correctly (Appendix 15). This method was recommended by Arscott et al. (1999) and Taua et al. (2014) for assessing the ability of people with ID to consent to research participation. The interviews were held in a private room in the hospital and took up to 30 minutes. Majority of the interviews were conducted in English with some phrases spoken in colloquial local dialect. Participant 5 spoke in Mandarin which was translated in English during the transcription process by the researcher who has a sound understanding of the Chinese language. Audio recording was used during the interview session. Participants were provided with a shopping voucher as a gesture of appreciation for taking part in the study.

Data Analysis

Research has shown that IPA can be used with people with ID, thus this method was selected to analyse the transcripts (Rose et al., 2019). The process of analysing the interview transcripts were the same as in Chapter 6, Method section under “Data analysis” (Page 207). The researcher undertook most of the analysis, noted down the descriptive, linguistic and conceptual comments in each transcript. Additional information about the participants’ behaviours, tone of voice, non-verbal cues and body language were also noted down to aid the data analysis and ‘meaning making’ of participants’ experiences in greater detail. Master

and emergent themes in each individual transcript were developed by writing down the initial codes on the left-hand column of the transcripts and categorising them based on patterns and connections that the researcher noticed in the raw data.

The researcher drew on his personal reflections from his professional experience and cultural knowledge to identify potential meanings of their experiences. In addition, thinking about the context of the participants in previous chapters helped the researcher to understand the reasons why participants emphasised certain aspects of their experiences and provided a clearer understanding of the issues.

Additional details were noted when analysing the transcripts of focus group discussions. There was an exploration of the interactions and dynamics between the participants in the focus group, such as how they shared ideas and thoughts during the interview, how they viewed themselves in relation to other members of the focus group, and how they provided emotional support to each other as they shared their experiences. The manner that participants positioned themselves when other members shared and made sense about their experiences, for example agreeing or disagreeing with others provided additional understanding whether the participants shared common meanings, beliefs and views based on their own personal experiences. The researcher also focused on their emotive language and the choice of words that they used during the interviews to describe their experiences as well as the exploration of their roles and relationships and what they meant for them. These include their descriptions of experiences with their family, their social support group and interactions with MHPs. Initial codes were generated and written on the left-hand side of the margin. The same process of categorisation by looking for connections between the

initial codes was carried out to form master themes and corresponding emergent themes in each of the focus group transcripts.

The last process involved looking for patterns and connections across the transcripts of the participants. All the master themes and corresponding emergent themes in the transcripts were extracted in a Word document. They were then printed and assigned into a separate colour for each participant and cut into separate strips which helped the researcher to look for connections and patterns. Some themes were re-categorised and relabelled to form master themes or sub-themes. The final list of master themes and corresponding sub-themes was produced. Quotes from the raw data were extracted to best illustrate the themes. More information on the data analysis process and participants' quotes can be found in Appendices 18 and 19.

Credibility checks

The same credibility checks were applied according to the Lincoln and Guba (1986) framework of trustworthiness described in Chapter 4, Method section under the "Trustworthiness in analysis" (Page 134).

The sample size was kept small which is suitable for this study (Smith et al., 2009) and the processes of auditing and verifying the IPA process were carried out as in Chapter 6, Method section (Page 136). Regular discussions were held with the supervisors for agreement of the themes and the quotes were verified to ensure that it represents the themes appropriately. Description of the demographic profile and data collection procedures were documented and the clinical supervisor made appropriate checks to ensure the data collection followed the ethical guidelines.

A reflective journal was used for bracketing and noting down thoughts, feelings and issues that the researcher encountered when carrying out the research. It was initially difficult to recruit participants and two potential participants were not eligible due to a lack of capacity. The researcher joined a participants' support group to make contact and talk to them to build trust and rapport. The researcher was aware that he may be viewed as a person with power in the service hierarchy. Therefore, he shared personal details about himself, carrying out activities such as watching YouTube videos with them and asking participants about their personal interest to reduce the power imbalance. This helped him to get to know the participants before the interview and understand more about their lived experiences. The participants became more comfortable and they shared their experiences freely and openly. More information about the researcher's reflections are described in the Appendix 26.

Results

Two focus groups and two individual interviews were carried out. Individual interviews were carried out for ISUs 5 and 6. ISUs 1 and 2 were interviewed together as were ISUs 3 and 4. Four main themes were identified following analysis. Table 7.3 shows the main themes, sub-themes and the number of participants contributing to each theme. The quotes were taken from ISUs' transcripts and italicised to illustrate the themes with clarity.

Table 7.3: Master themes, sub themes and the participants that contributed to each sub theme

Master themes	Sub-themes	Participants contributing to the themes
1. Awareness of mental health problems – *"Because I a bit… My brain…craziness…"*		3, 5 and 6
2. Yearn for a life outside the ward – *"I want to go home"*		3, 4, 5, 6
3. Interacting with other people	i. Family involvement - *"My family won't come fetch me"*	1, 3, 4, 5 and 6
	ii. The way mental health professionals treat me	1, 2, 3, 4, 5, 6
4. Finding purpose		2, 3, 5, 6

Master theme 1: Awareness of mental health problems – *"Because I a bit… My brain…craziness…"*

ISUs discussed the MH symptoms and reasons for inpatient admission and treatment. ISU 6 described having *"alcohol problem"* and identified himself as a troublemaker,

"I mah-poh (drunk) ah. Drunk, quarrel with my wife…I just yell, will fight with them (friends)…cause trouble." – ISU 6

He knew that his family had difficulty dealing with his behaviours and therefore he was sent to the hospital for treatment. This was also the case for ISU 3 who was admitted following an argument with his mother,

"My mum hit me. Then we got into argument, police came… The police bring me here, my mother hit me." – ISU 3

Both ISU 3 and 5 had difficulty to manage their emotions that led to frequent fights with others. ISU 5 showed some awareness of his symptoms, *"Because I a bit… My brain… craziness…know to fight with gangsters"* and reasons for inpatient treatment, *"My friend brings me here when I become too angry and can't sleep."*

ISUs were unaware of the reasons for taking medication but knew that they needed to comply in a structured setting. They expressed concerns about having side effects after taking them,

"…the body pain…will fall down… don't like it a bit… compulsory to take like that." – ISU 5

The structured setting in the hospital with a routine activity schedule and 24-hour care was appealing to one of the ISUs who believed that it helped him to manage his behaviours and emotions and he expressed an unwillingness to leave,

"I like to stay here. I don't want to shift other place. Other place not nice. All patient all new one. They fight me how? I get angry how? Down here, doctor check my problem." – ISU 6

Master theme 2: Yearn for a life outside the ward – *"I want to go home"*

Most of the ISUs viewed their stay in hospital negatively. The hospital environment was uncomfortable for them due to the noise level, *"Outside very noisy in the ward" (ISU 4).* Two of the ISUs reported a lack of privacy and frequently being disturbed by other patients staying the same ward,

"Patient ka-jiao (disturb) me. They keep shouting and shouting." – ISU 6

"This guy (name of patient) disturbs me every time. … every time disturb. Every time disturb me…" – ISU 3

Many of the ISUs reminisced about their past lives and one of the ISUs cried when describing the loss of his past, *"No more job. Closed down already" (ISU 4).* Another spoke about the activities that he previously did, *"At outside, I got a bit of this… ah… Baking a bit of stuff. Cooking",* viewed his hospital stay as time-limited, *"I think here a temporary place of settling down",* and wanted to find work, *"Because I want... I want to… to find a bit of work" (ISU 5).*

ISU 5' quotes suggest a desire to be 'normal' and wanting to be viewed positively by the public,

"To I think… apply for study like that…promote to university…want to find job for yourself." – ISU 5

Furthermore, participants expressed a strong desire to leave the hospital, *"I don't like staying here, I want to go home." (ISU 4).* This was reaffirmed by another ISU in the same focus group, *"He said he wants to go home" (ISU 3).* He additionally noted he was unable to return home despite his wish, *"I can't go home. Have to come here. I want to but can't go home. Stay here because my mum will hit me" (ISU 3).*

Master theme 3: Interacting with other people

ISUs reflected on the interactions with their family and MHPs in the hospital. They described the reactions of SMHPs and identified ideal attributes of SMHPs.

Sub theme 1: Family involvement - "My family won't come fetch me"

ISUs experienced a sense of isolation from their family because they had minimal involvement in their lives. One of them reported a strong sense of loneliness and sadness due to the absence of family support,

"Parents are no more already, parents are not here…. mother and father passed away." – ISU 4

Feelings of sadness, loneliness were also endorsed by another ISU, reflecting on his family reducing their involvement with him which left him feeling angry,

ISU 6: *My family won't come fetch me*
Interviewer: *How come?*
ISU 6: *Hmm. I tell them to come. My daughter also never come*
Interviewer: *How do you feel?*
ISU 6: *Angry.*

There were moments in the interview where ISUs expressed their affection or love to their family members, such as choosing the image of a heart and expressing feelings of happiness when they were visited by them,

"Mummy…I have a father too… (picks up the picture of heart) …close to me…mummy come and visit me." – ISU 1

Another ISU talked about his sibling and family members bringing food and spending time with him in the hospital which helped him to keep in contact with his family,

"Every Sunday when he's (brother) off work. Go and drink coffee. He buys coffee and popiah (snack) for me every day. My mother comes every time; every time she cooks porridge." – ISU 3

Many of the ISUs developed friendships to substitute their family and felt a sense of belonging in the hospital. One of them chose an image of a sun to represent the friendships he made while another shared how his friend showed care and concern towards him,

"No. only have one friend only (name of friend)…Buy drink give me." – ISU 6

Another stated he was in the hospital to be with his friend and helped him cope with his negative emotions as a result of being unable to return home, *"I stay with (name of person) in the same ward. I talk to him in the ward" (ISU 3)*.

Sub theme 2: The way mental health professionals treat me

One ISU talked about the role of SMHPs in relation to his physical health, *"I went to see doctor and doctor gave me cough medicine" (ISU 2).* ISUs viewed MHPs as having authority and they raised issues with them, for example informing them that other patients were disturbing them. They wanted SMHPs to take their issues seriously,

"Every time I have problem, I see doctor. Doctor checks problem." – ISU 6

"Important. Like if I got any issue with my body or anything/anyone disturbing me, I can tell the doctor." – ISU 3

Some of them shared their satisfaction with being treated well by SMHPs, *"Nurse sayang (treat me affectionately) me, very good" (ISU 1)* for example bringing in food, not scolding patients and engaging in activities to build rapport,

ISU 5: I think… ah... the nurse buy me some curry puff to makan (eat)

Interviewer: How she treat you?

ISU 5: She is concern about me.

Interviewer: How does she show concern for you?

ISU 5: She will help me do my best. She is concerned about me.

Interviewer: Is there anything you like about her?

ISU 5: She don't everyday scold and shout. And don't try to scold vulgarities. And she and I plant some flowers inside the hospital garden.

The image of a 'thumbs up' or a smiling face was frequently chosen by ISU participants to denote their satisfaction with the services. When asked about the ideal attributes of SMHPs, they wanted SMHPs to treat them kindly, *"The doctor's kind" (ISU 6),* for example *"show mercy (compassion), Treat me nice. Good heart. Someone that enjoy working with me" (ISU 5).* Others chose the image of the spanner to indicate the support they received in acquiring new skills, *"He taught me how to use a screwdriver." (ISU 2).*

In contrast, one participant said that SMHPs were not approachable and lacked empathy, *"The doctor very rude to me, very rude",* he did not like them because they used restraints on him, *"…because every time tie me so I don't like the doctor." (ISU 4).* He further recounted the impact of negative reactions from SMHPs,

"I don't like the nurse. The nurse makes me cry…scolds me every time." – ISU 4

Many of the ISUs valued the advice provided by SMHPs though some felt they were dismissive and provided superficial advice without understanding their real concerns, *"The doctor asked him to ignore the patient …he doesn't want to…so it's not helpful" (ISU 4).* ISUs emphasised the importance of SMHPs spending time with them to understand them better. One participant did not want SMHPs to make decisions for them,

Interviewer: *Would you like the doctor to decide what's best for you?*

ISU 3: *Decide for me?*

Interviewer: *It means like help to make decisions in life for you. Would that be important to you?*

ISU 3: *I don't want that.*

Master theme 4: Finding purpose

Having some form of activity or work during their inpatient stay was important for ISUs. One of them described learning new skills and expressed hopes about being able to perform tasks in the hospital,

> *"I stay here and learnt how to play a bit of mahjong. Then after that I think… I want to… know how to make kite …. help to do a bit of simple jobs." – ISU 5*

They want to become more independent and rely less on SMHPs for assistance, *"They take care of me…I have to take care of myself" (ISU 5).* Another viewed himself being of service to others by carrying out basic chores and feeling a sense of pride when he received an allowance,

> *"I do work operations…little jobs…mop, sweep… If they (patient) pang-sai (defecate), all mah-poh, help them wash backside… Work one month one time pay…" – ISU 6*

Some ISUs identified their purpose as being a supportive and protective friend. One participant talked about how he always made time to comfort his friend when his friend was treated badly,

"…yeah, he's my friend… I've known (name of friend) for five years…will come to find him when the nurse scolds him every time…joking with him…"

– ISU 3

Discussion

Findings of this study provide a unique insight into the experiences of inpatients with ID and MH. IPA identified four master themes relating to understanding their MH problems, how they make sense of their stay in the hospital, their interactions with their family and SMHPs and lastly, seeking a sense of purpose.

There were initial concerns that the SUs in the study may not provide rich and detailed data that could be used for IPA as it requires in-depth descriptive and/or reflective data obtained from the participants. Rose et al. (2019) found that some researchers provide additional supports when interviewing with people with ID, such as having carers present and using alternative communicative approaches. The SUs in the focus groups were familiar with each other which helped them to feel comfortable during the interviews. Short, fragmented comments made by the research participants were clarified and expanded upon using additional questions, for example using 'how' questions as recommended by Petitmengin (2006) and adapting the questions to be short, clear and concrete (Dagnan et al., 2016). This form of scaffolding joins the short, fragmented comments together to make the data more coherent and richer so that it can be used for analysis.

Resources adapted from Unwin et al. (2016) help to facilitate the discussion and showed that it is possible to actively engage with SUs who have limited verbal communication skills. Although the Tools for Talking resource was developed in the UK for a specific population, cultural adaptations were made that included changing certain words, for example "my

support worker" to "my training officer/healthcare worker" and "my advocate" to "my job coach". People with ID participating in research studies may experience difficulties in communicating and sharing their views (Robinson et al., 2016). Having activity-based interactions with the researcher/interviewer can help this client group to express themselves more effectively using pictures and symbols. Some SUs in the study were able to choose symbols such as the heart, sun and spanner to represent the significance of specific people in their lives. The use of the Tools for Talking resources could be expanded in other areas of research in non-western countries involving people with ID so that they have greater opportunities for their voices to be heard and their views being taken into consideration when evaluating current or developing future services.

The findings suggest that ISUs have some awareness of their MH conditions. In contrast to a previous study (Cookson & Dickson, 2010) which highlighted participants' awareness of their psychotic symptoms and psychiatric diagnoses, the SUs in this study did not identify with their psychiatric diagnoses and had trouble understanding their symptoms. The findings of this study also contrast with Taua et al. (2015) who found that some individuals with ID are able to evaluate the effectiveness of medication in treating their symptoms and can consider alternative non-pharmacological approaches. The current findings confirm observations from Robinson et al. (2016) that participants describe their emotional difficulties rather than their MH symptoms or diagnoses.

The lack of identification with their psychiatric label and poor awareness of their MH symptoms found in the current study may be due to cognitive deficits. However, cultural differences may also play a role where family members do not want MHPs to provide

information to their relative with ID about their MH conditions (Bernal, 2008), hence it may be possible that the SUs in the study were not informed about their MH conditions.

ISUs know they are 'different' and separated from their communities as a result of their intellectual and emotional difficulties, also observed in participants of Robinson et al. (2016) study. Themes of disempowerment and seclusion have commonly been found in other studies that involved people with ID receiving inpatient MH services and suggest that many in-patients are dissatisfied with the hospital environment, the treatment process and negative reactions from MHPs (Donner et al., 2010; Longo & Scior, 2004). In contrast to Donner et al. (2010) and Longo and Scior (2004), the current study found feelings of grief and sadness among the ISUs when they described their loss of emotional ties in their community and being unable to work. This suggests that integration in the community is important for the ISU participants where they want to interact with others and be a part of the community as reflected by their aspirations, such as wanting opportunities to study, work and have social networks. They also value self-determination, having a say in how they live their lives and who takes care of them.

ISUs recognise their stigmatised status in society after their family decline to take them back or reduced contact with them. A lack of societal acceptance may affect the ISUs' ability to identify positive aspects of themselves. They believe their situation would improve if they are allowed to leave the hospital and were provided with opportunities to integrate in their own communities. Jahoda and Markova (2004) noted that individuals with ID have to cope with societal stigma when they relocate from their communities to institutionalised settings. Similarly, ISUs have to deal with stigma and process their emotional reactions in relation to their interactions with family members and SMHPs. ISUs experience a poor sense of self and

feelings of sadness when they encounter family rejection and/or negative reactions from SMHPs. This existence of stigma around MH and ID in a non-western culture are in line with findings from Robinson et al. (2016) and Mattock et al. (2020) that found the negative impact of stigma on self-esteem and self-identity of individuals with ID. ISUs attempt to reconstruct their own self-identity through various means, such as being a supportive friend or carrying out acts of service to help others in the hospital. In doing so, they engage in meaningful activities which not only alleviated their boredom as described by Taua et al. (2015) but also enable them to rebuild their self-identity and improve their self-esteem.

The findings of the study indicate a strong desire for family members to be involved during inpatient stay. Other studies of inpatients with ID included the voices and perspectives of FCs who acted as their advocates during MH treatment (Donner et al., 2010; Longo & Scior, 2004; Scior & Longo, 2005). Unfortunately, in the current study there are low levels of family involvement observed, likely due to high caregiving burden and stress experienced by family members that leave them unwilling to continue or resume their caregiving responsibilities. A study conducted in a Chinese society revealed that people with ID require high levels of physical care which affects the emotional well-being of their FCs negatively (Li et al., 2012). There is a likelihood that family members experience high levels of distress when dealing with their relative's MH problems and prefer professional staff to take care of their relative in an institutionalised setting.

Developing social interactions with others in the hospital alleviated feelings of loneliness in ISU participants. Participants with ID of qualitative studies conducted in other countries did not talk about their social interactions and friendships during inpatient treatment. Yet, there is an acknowledgement that having friends is important to a person's well-being and

research has found that having a social network of friends improves quality of life outcomes for people with ID (Friedman & Rizzolo, 2017; van Asselt-Goverts et al., 2015). However this is largely neglected by service providers and people with ID are found to have poor friendships, lack support in activities with their friends in institutionalised setting and few have non-disabled friends in the community (Emerson & McVilly, 2004). People with ID are capable of making close friendships and enjoying mutual activities together (Knox & Hickson, 2001). This suggests people with ID value having friendships like the rest of the population and service providers should work on encouraging and supporting them to develop meaningful friendships and provide opportunities for them to interact with others in the community.

The personal qualities of SMHPs impact on the relationships and interactions with ISUs who identify desirable interpersonal attributes and want SMHPs to listen and address their concerns appropriately. SUs prefer SMHPs who show willingness to work with them and help to promote their competency (Lloyd et al., 2013; Stenfert Kroese et al., 2013). The current findings also show some differences by which there is a strong deference towards SMHPs and ISUs report a sense of safety under their care, which can be explained by attachment theory which predicts the development of a secure attachment with MHPs in an institutionalised environment (Berry & Drake, 2018). However, this secure attachment can break down when MHPs treat them harshly and use physical restraints. ISUs also wanted SMHPs to listen to their difficulties, provide them with advice and training to enhance their competency which is in line with the findings of Stenfert Kroese et al. (2013) and Mattock et al. (2020).

Limitations

The majority of the participants in the study had moderate level of cognitive functioning with moderate to severe MH problems and difficulties to express themselves, hence there could have been misinterpretation of data during the analysis despite efforts made to help them verbalise their experiences. Credibility checks were carried out to ensure that the data remained trustworthy and attempts were made to reduce researcher's biases during the analysis process. The themes identified were checked to ensure that they remained grounded in the data.

Participants provided short quotes and scaffolding was provided to guide them to elaborate about their experiences, but some of them could not provide in-depth responses that includes reflecting on their experiences because of their cognitive ability. Moreover, the study was conducted mainly in English which was not the main language for participants, hence affecting the richness of data. This could result in certain participants contributing more and their thoughts being more prominent than others. There were efforts made for participants to communicate in an alternative language and the focus group was kept small to ensure that everyone had opportunities to share their experiences and views. Perhaps, future studies could explore expanding sample size of individuals with ID to get a wider breath of data and allow them to express themselves in their preferred language during interview.

Implications

Recommendations to improve the service delivery and inpatient care for people with ID based on the results of the study include adopting the concept of person-centred care (Beadle-Brown, 2006). Singapore has adopted the principles of person-centred care within

its own local culture and adopt at least part of O'Brien (1992) service framework model by supporting and training people with ID to maximise their independence and self-care (Lim & Sim, 2001). Further advances are recommended to push the boundaries of person-centred care by facilitating self-determination, decision-making about activities and making choices about where and whom to live with (Beadle-Brown et al., 2012). Future development of services could focus on helping ISUs to develop friendships, providing opportunities to promote choice and autonomy through supported decision-making and considering alternative housing with opportunities to be closer to their communities.

The quality of the relationships with their SMHPs has an impact on ISUs' coping and adjustment in an institutionalised environment. In addition to acquiring theoretical knowledge of ID, both SMHPs and MMHPs should consider the most effective ways to build trust and bond with ISUs instead of using restraints and medication to address their behaviours. Lloyd et al. (2013) found that a secure attachment relationship between MHPs and ISUs provides a sense of safety and security which meets ISUs emotional needs. People with ID without the support and involvement of their family may benefit from having a secure attachment and trusting relationships with their MHPs to ameliorate their feelings of loneliness and isolation. Therefore, recommendations are made for training programmes to include learning basic counselling techniques, such as active listening and micro-skills to attend to ISUs emotional needs and develop rapport with them.

Early access to family-based interventions should also be considered to address the coping and emotional well-being of FCs when their relatives are admitted for inpatient treatment. FCs may feel exasperated and have high emotional distress that can lead to a breakdown in the relationship with their relative and discontinuation of their caregiver responsibilities.

This has a detrimental effect on their relatives as they become isolated from their communities and efforts to reintegrate them then become more difficult. FCs of relatives with severe issues and high care needs benefit from having more support during the early period of treatment, in order to maintain and improve their relationship with relative with ID as well as to provide them with skills and resources to address the caregiving challenges they face. SMHPs can discuss the different ways to cope with the family care burden, such as considering respite care and having onsite care staff to assist FCs with their relative's care needs.

Conclusions

The present study aimed to explore and understand the experiences of inpatients with ID and MH problems in Singapore. The findings suggest that ISUs are focused on their emotional difficulties rather than the psychiatric diagnoses they have been labelled with. There is a low level of family involvement for this population that leaves them separated from their communities. The themes indicate feelings of sadness and loneliness for which ISUs try to find ways to address, such as engaging in activities and making friendships in the hospital. As a result, ISUs recreate their sense of self-identity and find purpose and express a desire for more participation in the community through work opportunities. They also wish to be reunited with their families and keep a sense of belonging with their community. This study also highlights that ISUs value SMHPs who take time to understand them better whether they access mainstream or specialist services.

The next study explores the experiences of SUs receiving outpatient specialist MH ID service in Singapore and how they make sense of their MH problems.

Chapter 8: Study 5 - What are the experiences of service users receiving outpatient specialist mental health intellectual disability service in Singapore?

Introduction

Previous chapters highlighted a high prevalence rate of people with ID developing MH problems and the importance of early treatment (Birchwood & Singh, 2013; Patel et al., 2007; Yen et al., 2009). Researchers have started exploring first person narrative accounts of people with ID of their MH problems in order to gain insight into coping styles and meaning making (Raghavan, 2004). Qualitative research on MH experiences of people with ID has been carried out in various countries such as the UK, Canada and Australia to understand about how they make sense of their MH problems and evaluate the services they receive (Lloyd et al., 2013; Lunsky & Gracey, 2009; O'Brien & Rose, 2010; Taua et al., 2015). Significant themes around quality of interactions and working relationships with MHPs, a desire to have meaningful activity engagement in the community and identifying desirable qualities of MHPs were commonly found in these studies. Other research studies also explored the views and experiences of people with ID receiving psychological interventions (Lewis et al., 2016; MacMahon et al., 2015; Pert et al., 2013; Stenfert Kroese et al., 2016; Thomson & Johnson, 2017) which found that they understood the tenets of the therapeutic model and benefitted from learning coping strategies to manage their emotional difficulties.

Studies in the UK have explored the experiences of people with ID in the community receiving outpatient MH services (Mattock et al., 2020; Robinson et al., 2016). There has as yet been no research to provide insight into understanding the personal experiences of people with ID and MH problems receiving outpatient specialist MH services in Singapore. It

remains unknown how they view the outpatient specialist MH ID service since its establishment in 2011. Therefore, this study aims to explore the experiences of SUs receiving outpatient specialist MH ID service and how they make sense of their own MH problems.

Method

Participants

Participants were recruited from a specialist MH outpatient service for adults with ID in a tertiary hospital in Singapore. The inclusion and exclusion criteria were the same as those described in Chapter 7 except that they had to receive outpatient MH services. The recruitment was subsequently expanded to include those with ASD because of low rate of recruitment.

Participants were five adults with ND, 3 men and 2 women aged between 21 and 29 years old (median age 25). Three of them were of Chinese ethnicity and the others were Malay and Indian respectively. All the participants lived with their family members. Three attended supported work employment and the other two were unemployed. The information regarding participants' diagnoses and MH problems were obtained from their clinical records provided by the clinical supervisor. Four of the participants had multiple co-morbid MH problems and three of them experienced symptoms of psychosis.

Participants in the study were de-identified and referred to by the acronym OSU (Outpatient Service User) with the corresponding numbers allocated in Table 8.1.

Table 8.1: Demographics of Outpatient Service Users

Participant (OSU)	Age range	Gender	Ethnicity	Employment Status	Neurodevelopmental and MH labels
1	25-30	F	Malay	Unemployed	ID, psychosis, depression
2	20-25	M	Chinese	supported work employment	Borderline ID, ASD, aggressive behaviours, social anxiety
3	20-25	F	Chinese	supported work employment	ASD, psychosis
4	20-25	M	Chinese	supported work employment	Borderline ID, ASD, Obsessive compulsive disorder (OCD)
5	25-30	M	Indian	Unemployed	ASD, Schizophrenia, OCD

Interview Schedule

The interview schedule (Appendix 16) consisted of the same set of questions and resources adapted from Unwin et al. (2016) which can be found in Chapter 7, Method section (Table 7.2, Page 250). An example of the activity with OSUs can be found in Appendix 22.

Procedure

The participants were recruited using the same procedures as described in Chapter 7 Method section (Page 250).

Data Analysis

The transcripts were analysed in the same way as detailed in Chapter 7, Method section (Page 249). The researcher read and re-read the transcripts to familiarise himself with the data. Different types of comments were noted on the left-hand column of the transcripts and initial codes were developed which were written in the right-hand column of the transcripts. The initial codes were then printed on separate strips of paper and re-arranged based on similar connections and pattens to form master themes with corresponding emergent themes. This process was repeated across all of the transcripts. Additional information regarding the participants' interactions and dynamics with each other during the focus group was noted down as part of the analytic process.

The last stage of the analysis involved extracting all of the master themes and emergent themes from the transcripts on a separate Word document. Similar themes across the participants were identified and re-categorised. Some of the themes were relabelled to better reflect the essence of the experiences. A final table of master themes and sub themes was compiled and quotes were selected from the raw extracts to illustrate the themes. More information on the data analysis process and participants' quotes can be found on Appendices 21 and 23.

Credibility checks

Credibility checks were carried out in the same manner as described in Chapter 7, Method section (Page 253). A reflexive journal was used for bracketing and noting down thoughts, feelings and issues that the researcher encountered when carrying out the research. The recruitment rate was slow which could be explained by an initial lack of rapport and trust between the researcher and the participants. One potential participant was not selected

because they did not understand what was required in the study. Similar efforts described in Chapter 7 were made by the researcher to join a support group where the researcher introduced himself and got to know the participants. Some of the participants found the focus group setting more comfortable and they built on each other's ideas to elaborate about their experiences. One participant needed the support of their parent because of the distress they experienced when recounting their experiences. The researcher used prompts and binary options to clarify meaning with the participants if necessary. The researcher checked and rechecked their emotional status and provided de-briefings for the participants. More information about the researcher's reflections are described in the Appendix 26.

Results

OSU 1 and 5 were interviewed individually and OSU 2, 3 and 4 joined the focus group interview. Four master themes were identified following analysis. Table 8.2 shows the list of main themes, sub-themes of OSUs and the number of OSUs contributing to each sub-theme. The quotes were taken from the OSUs and italicised to illustrate the themes with clarity.

Table 8.2: Master themes, sub themes and the participants that contributed to each sub theme

Master themes	Sub themes	Participants contributing to the themes
1. Sense of self - *"I feel angry with myself, I blame myself"*		1, 3, 5
	i. Family support *"Parents, they care for me"*	1, 2, 3, 4, 5

2. People who matter to me	ii. Community support *"Open the door"*	1, 2, 3, 4, 5
	iii. Interactions with specialist mental health professionals	1, 2, 3, 4, 5
3: Choice and autonomy - *"Just respect me"*		1, 2, 3, 4, 5
4. Hopes and dreams		1, 2, 3, 5

Master theme 1: Sense of self - "I feel angry with myself, I blame myself"

This theme describes how OSUs made sense of their mental health problems. OSUs spoke of the impact of MH problems on their sense of identity and how they coped with their problems. When asked to share their experiences of having MH problems, one of the OSUs felt angry and blamed herself, *"I feel angry with myself, I blame myself, I bang and hurt myself" (OSU 1).* Another OSU hesitated and talked about previous stressors that triggered his MH problems,

> *"Ever since I lost my recent job, it has been days..(long pause)...I became very stressed out with the job because I got to meet the productivity level so that they can employ me further in the job." – OSU 5*

He demonstrated a level of understanding of his own MH problems, *"…they diagnosed me with Asperger's syndrome. Eventually, they also discovered I have OCD".* When asked about the impact of these diagnoses, he recalled having intrusive delusions, feeling a sense of worthlessness and a low sense of self, *"The voices are coming and shouting at me, saying you are bad, you are disgusting… all those things started to overwhelm me" (OSU 5).* He

went on to explain the reason for his admission which was because of his difficulty coping with work demands, *"The only issue that I face is just the stress levels when in the job"* and stated that his symptoms had improved, *"It has reduced dramatically now because I have been taking my medication".*

OSU 1 admitted her self-esteem was affected, *"I cannot improve, I cannot do anything".* Another OSU admitted viewing herself negatively because of frequent negative ruminations, *"I keep thinking about the past…" (OSU 3)* and struggled to find positive meaning in her experiences. There was a strong expectation of recovery for OSU 5, *"I can overcome this issue and focus on my life. I want to get over it"*, because he did not want others, specifically his parents, to view him differently, *"I behave normally in front of them",* and wanted to meet his parents' expectations,

"They encouraged me to get better because they have been taking care of my life and wants me to be more independent." – OSU 5

Master theme 2: People who matter to me

This theme encapsulated the important people in the lives of the OSUs. They identified people who helped them to address their MH problems and the desirable attributes of SMHPs.

Sub theme 1: Family Support - "Parents, they care for me"

All the OSUs reported to have strong support from their parents*, "Because my parents are important persons of the family" (OSU 4).* OSU 4 chose an image of a widening road and wrote *"leader"* to describe his parents' care and their involvement in decision-making

regarding his life. OSU 1 described the support of her father, *"calm me down when I am upset"* and felt helpless and alone when her father was not around,

"Father is going to hospital and makes me upset. I miss and love you father. I feel so upset. Nobody talked to me. Nobody wants to kiss me." – OSU 1

OSUs further elaborated on the assistance from their parents. OSU 2 stated that his mother provided advice when he encountered problems, *"Help me with any problems, any difficulties. Difficulties with things like surviving. About things like surviving life".* OSU 5 found his father's advice useful for coping with MH problems,

"He said to ignore the voices, distract yourself and continue to do something else. That is what he suggested me to do." – OSU 5

Most of the OSUs chose an image of a heart to symbolise parental love, *"This one, mother, father love me" (OSU 2).* When asked about their feelings regarding the time they spend with their parents, they reported feeling *"happy"* (OSU 1) to spend time and engage in activities with them,

"On my birthday, my mum brings me out." – OSU 2

"I play jogging, make funny faces and jokes with him"- OSU 1

Sub theme 2: Community Support – "Open the door"

Many of the OSUs spoke about the support they received from community agencies. OSU 3 enjoyed attending courses to learn new skills and meet new friends, *"Another support is from my empowerment course, hope to learn to do skills and have my friends".* Another OSU chose the image of a sun because he was grateful for the opportunity, *"they gave me work"* and the support he received in work, *"they help me with providing instructions" (OSU 2).*

This was similarly endorsed by OSU 3 who chose the image of the key and elaborated her reasons for her choice,

Interviewer: Why did you choose the key?
OSU 3: Because she (community support staff) gave me job training opportunities.
Interviewer: What does the key represent for you?
OSU 3: Open the door.

When asked about their experiences interacting with the support staff in the community services, the majority of the OSUs chose the image of a 'thumbs up' to indicate high levels of satisfaction with the service. OSU 5 identified the support staff as *"the one that is helping me get a job"*. Some of them shared that the support staff were sincere when talking to them. One of them further shared that she enjoyed her time talking to the employment agency staff because they were interested in her future,

"She's quite friendly. She asked me what my next step is. Like after employment program, where I'm going." – OSU 3

Another OSU concurred and talked to them about his personal feelings and issues that he encountered,

Interviewer: Is there any particular person that you talk to more?
OSU 4: Maybe talk about...the closest I talk to is my case manager.
Interviewer: What does the case manager do?
OSU 4: He just ask me how I feel and all that.

However, one of the OSUs did not like going to the community agencies and experienced anxiety symptoms because she did not want to be separated from her father,

"I don't want to there. I want to "jaga" (take care) of my father." – OSU 1

Sub-theme 3: Interactions with specialist mental health professionals

One OSU talked about her negative experiences with SMHPs and shared her dislike towards them,

> *"I don't like doctors, doctors are very angry. They scold me for being angry (shouting)." – OSU 1*

She further shared being *"uncomfortable"* about attending subsequent treatments with the medical SMHPs, *"I don't like, feel angry …I don't* want *to go hospital..."* Other OSUs were satisfied with the services provided by SMHPs and found them helpful,

> *"He (the doctor) gave me medication. Psychologist gave me suggestion and tips how to improve my behaviour, how to prevent aggressive behaviour, learn coping strategies. Those are the things that she gave me to do." – OSU 5*

Many of the OSUs chose the image of 'thumbs up' and wrote *"helpful"* and *"good doctor"* to indicate their positive feedback, *"Helpful to me on how to take good care of my health" (OSU 2).* One of them chose an image of a plaster and smiling face to denote her interactions with her SMHP,

> *Interviewer: You chose a plaster. Why is that so?*
> *OSU 3: Because she listens to my problems and she advises me.*
> *Interviewer: I also noticed you put a smiley face for the occupational therapist.*
> *OSU 3: The occupational therapist always encourages me.*

Like OSU 1, OSU 3 did not have positive interactions with medical staff,

> *Interviewer: You put there a question mark beside the doctor. Why do you put a question mark?*
> *OSU 3: Because I rarely see him.*

Interviewer: How do you find him?

OSU 3: Don't like him.

Interviewer: Any reason why you don't like him?

OSU 3: No, I just don't like him.

This was in contrast with another OSU who found that his concerns were addressed by his specialist medical doctor during the consultation session,

"I speak to the doctor, he'll listen. When I visit the doctor, the doctor will listen." - OSU 2

Indeed, many of the OSUs reported that they would like their SMHP to be good listeners and take time to understand them as individuals,

"My work, religion, family are my life that the healthcare professional needs to understand." – OSU 5

Having a trusting relationship with SMHPs is important for OSUs as they identified them as having their best interests at heart and as such, would adhere to their advice and feel supported by their encouragement,

Interviewer: How is she a good healthcare professional to you?

OSU 4: Because she explained the good things to me. Like good things you should do. Bad things you should not do.

Interviewer: Why is she important for you?

OSU 4: She wants me to keep fit and healthy.

Interviewer: Have you been following her advice?

OSU 4: Yes, running at jogging track.

Some of the OSUs disliked it when SMHPs ignored them, especially when they were hospitalised and felt a lack of opportunities to express their views or opinions or discussion about their treatment,

Interviewer: Did you talk to the doctors?

OSU 1: No

Interviewer: How come?

OSU 1: Doctor keep quiet only

Interviewer: Nobody came to talk to you?

OSU 1: No. They keep quiet, they never talk to me.

Master theme 3: Choice and autonomy - *"Just respect me"*

The importance of choice and autonomy was emphasized by OSUs in this theme. Many of the OSUs would like SMHPs to respect the choices that they make, *"I wanted to be treated as an individual rather than being ignored." (OSU 5).* This is pertinent for one of them as she recalled how SMHPs treated her and used excessive force to tie her up when she was hospitalised,

> *"They said, "you want to stay here or you want me to admit you?" Then I stayed there… They.....they (slight agitated) tie up me from behind until my leg, tie me, pull me like that...I shout with my mouth...where is my father, where is my father? Then, I cannot come out, then I pull the door also cannot. I cannot come out." – OSU 1*

She was crying and sobbing when recounting this experience. The majority of the OSUs wanted to have choices such as having the autonomy to spend time with their loved ones in the community,

> *"I go to the shopping mall. I also do things. I also go and eat and hang out with friends. Eat at the same place and hang out. Also can do other things, celebrate and eat." – OSU 2*

Another OSU talked about the freedom to make friends in the community and access places,

"I met her (friend) in my workplace… Sometimes happy things. For example attending church because it is my favourite." – OSU 4

Similarly, OSU 1 and 5 talked about carrying out activities in their house without restrictions, "*reading books, watching television, listening to music" (OSU 5),* and how much they valued them, *"I'm happy. Watch boxing on TV" (OSU 1).* OSU 1 expressed an awareness that her choices were sometimes not respected by others and pleaded SMHPs to respect them,

(Took deep breaths before speaking) "I want the doctor to allow me to take care of my father, I miss my father." – OSU 1

OSU 5 summed up succinctly how he wanted SMHPs to acknowledge the choices he made in his life and respect the autonomy that he has in his relationships with others,

"Just respect my life, my family, my friends, people that I talk to. In general, just respect me." – OSU 5

Master theme 4: Hopes and dreams

Many of the OSUs shared their future goals. Establishing and maintaining social contacts for example,

"I want to talk more with my online friend. Every time I write I'm sad, then he will talk to me to cheer me up." – OSU 3

One OSU yearned for mental health problems not to affect his life in the future and identified his goal as getting a job. He described working hard and practising the strategies taught by SMHPs,

"Read different books to challenge my mind, don't be so rigid in my thinking and try to be open-minded to learn new information and topics.

having to do worksheets to help me understand and how to handle stress."
– OSU 5

Three of the OSUs identified work as an important way to keep themselves connected to the community and wanted opportunities to apply the skills that they learned,

"I hope to join a course or find work. Then I have my friends, make new friends together…spend time with me." – OSU 2

OSU 1 hoped to recover from her emotional difficulties so that she could look after her father. She further elaborated that she wanted to spend more time with him given his ill health,

"Father is going hospital and for operation, he said that his leg cannot walk. I want to help take care my father." – OSU 1

Discussion

This study explored the experiences of OSUs receiving outpatient specialist MH services in the hospital. There has been no such previous study in Singapore and this study shows a unique perspective of how OSUs ascribe meaning to their MH experiences and the services they receive. Findings reveal four main themes relating to their self-concept, the level of support they receive, their desires to have autonomy over their lives and their future goals.

The current study initially aimed to include only OSUs with ID in keeping to the principle of having homogenous samples for IPA studies (Smith et al., 2009) but this was difficult to achieve due to a low recruitment rate. A possible reason is the level of stigma towards MH problems in Singapore that discourage potential participants to talk about their MH experiences (Chong et al., 2007; Subramaniam et al., 2017). A decision was made during the

recruitment phase (upon consultation with research and clinical supervisors) to widen the inclusion criteria to include other types of ND and those with borderline ID. Attempts were made to ensure homogeneity in the sample, such as ensuring the severity of the MH problems were the same among the participants. Moreover, all the OSUs were receiving outpatient MH services in the hospital and were living with their family at the time of recruitment. The OSUs in the study faced similar issues (such as integration in the community and employment) and MH needs when accessing outpatient MH services despite their varying cognitive abilities. Care was taken to ensure that the views of the OSUs were well-represented across the themes.

The OSUs in this study showed some understanding of their MH problems and tried to make sense of them with reference to their self-identity and self-esteem. Most expressed a negative sense of self and one participant (OSU 5) tried to maintain a positive self by focusing on his recovery and avoided dwelling on his MH problems. These themes identified in the current study are largely similar to those found in Jahoda et al. (2010) who explored the impact of MH problems on the sense of self in people with ID as they navigated the demands of adulthood and community participation. They found a strong internal sense of self-blame in some of their participants which was influenced by their environment and culture. Singapore is a developed South East Asian country known for its competitive economy with high social and economic inequalities (Yahya, 2014). As the participants did not have full employment, it is likely that they perceive themselves negatively because of being unable to keep pace with others and contribute economically to their families and wider society. This suggests a strong cultural influence on OSUs wanting to find employment so that they could be accepted and become part of their community.

There is a strong emphasis on helping people with mild ND and mental health problems to have some form of employment and for this they receive support from community agencies. Unlike Robinson et al. (2016) who found support care staff provided assistance to people with ID in their ADLs for example shopping and managing medication, support staff in Singapore provide support, resources and training in order to improve employment opportunities for people with ND so that this group can be gainfully employed and become part of the Singapore labour workforce (Kurochi, 2019; Poon, 2015). Hence, OSUs in this current study identify their meaningful roles within their community as being closely related to employment. The high satisfaction towards the community services can be explained by the positive efforts that these services make to meet the needs of the OSUs in securing employment and providing job training.

A possible explanation to account for the positive interactions between SMHPs and OSUs reported here unlike the study conducted by O'Brien and Rose (2010) is the level of trust and rapport developed over time. OSUs expressed that SMHPs are genuine and sincere about wanting to improve their lives, for example offering a listening ear and providing advice or strategies to address their problems. These SMHPs are viewed more favourably than those who are not keen to talk or had infrequent contact with them which could be attributed to level of training and experience working with this specific population. Some OSUs reported that SMHPs treat them with respect and as an individual and felt a sense of familiarity with them and comfortable enough to talk about their personal problems.

Coercion and restraints used by SMHPs affect the therapeutic relationship and led to a perceived sense of threat as was described by OSU 1 in this study. The use of restraints has been found to be strongly associated with challenging behaviours such as shouting and

demanding excessive attention from staff (Fitton & Jones, 2018). Most studies indicate a negative view of the use of restraints among people with ID and cause a rupture in the relationships with MHPs (Fish & Hatton, 2017; Jones & Stenfert Kroese, 2007). The trauma that OSU 1 experienced during her hospitalisation that negatively impacted her future relationships and interactions with subsequent SMHPs are in line with previous findings of studies involving women with ID who had experienced the trauma of being restrained and a lack of respect from MHPs (Lunsky & Gracey, 2009). Having an unpleasant encounter or negative experiences is likely to have an impact on SUs' future relationships and interactions with MHPs, which in turn can reduce their motivation and willingness to comply with treatment. Hence, MHPs need to consider alternative ways of addressing emotional distress, without the use of medication or restraints in order to develop trust and positive therapeutic relationships with SUs.

High levels of family involvement and support are found in the current study unlike a number of UK studies (Cookson & Dickson, 2010; O'Brien & Rose, 2010; Robinson et al., 2016). Wong and Chan (2012) identified family members as important partners to improve the outcomes and independence of people with ID or ND in Asian cultures. Having a close relationship with family members is helpful for all the OSUs in this study whom they depend on their advice and support when dealing with their MH problems. Collectivist values where there is a strong deference towards people in hierarchical positions of authority may explain the findings that OSUs turn to family and SMHPs for support and assistance. The important role of family is emphasized in Singapore in which the responsibility for the welfare and care of its citizens lies with their own families instead of the state (Hwang, 2018). Therefore, families are expected to take on the necessary role to care for their relatives with disabilities and not to depend on state welfare or assistance. As such they continue to be heavily

involved in their relatives' lives during adulthood with minimal state intervention. Adults with ID therefore particularly value their families' involvement and time with them.

OSUs in the current study clearly stated that they want choices and autonomy over their lives, such as deciding where they want to live and having opportunities to participate in the community. There is a general view among OSUs that they want SMHPs to treat them with respect and listen to their views. Other research studies involving different groups of people with ND also report that they want to have more say and input regarding how they lead their lives and that they feel anger when MHPs demean or disrespect them (Crane et al., 2019; O'Brien & Rose, 2010). A positive thing to note is that OSUs reported that the employment agencies are giving them choices in activities and interests and opportunities to be part of their community through work and social networks.

Implications

Hospital policy makers and university course administrators may find the results of the current study useful when developing training programmes for MHPs and other relevant students to improve their attitudes of people with ID. OSUs are focused on personal attributes of SMHPs and want them to be respectful and have active listening and communication skills so they feel comfortable to talk and seek their advice.

Services should consider involving SUs more during discussion about their treatment plans and facilitate them to decide how they want to live their lives. MHPs should consider spending more time to understand SUs more instead of merely focusing on addressing the symptoms. O'Brien (1992) states five service accomplishments for services catering for people with disabilities that MHPs should consider. One of these accomplishments is providing opportunities for SUs to have a presence in the community through work or

spending time with family. Community support and family involvement are essential to help this group of the population to integrate in their communities following recovery, hence MHPs should consider working beyond the confines of their hospital environment to provide services nearer to the local community of OSUs. PBS (Sailor et al., 2008) can help MHPs to identify the function of the behavioural problems and develop a support plan that considers alternative strategies such as the low arousal approach to reduce the frequency of restraints being used (Allen, 2009; McDonnell et al., 2018).

Conclusions

This is the first study that has sought to ask people with ND and MH problems in Singapore about their experiences and how they view the services. The findings indicate that people with ND have an awareness of their condition and would like more choice and control over their lives. People with ND are shown to be able to participate and engage in research when they receive support for their communication needs. Future disability-related research in Singapore can consider more ways of involving this specific group as participants and more effort is recommended to strive towards promoting their independence and participation in their own communities through engaging them in work, social and leisure activities.

The next part summarises and compares the themes across the five studies to discuss the implications of the findings for practice, policy and MH services for people with ID in Singapore.

PART III: Bringing everything together

Chapter 9: Overall Discussion

This thesis has provided an insight into the experiences of professionals in Singapore working in mainstream MH and specialist MH ID services, as well as into the experiences of FCs and SUs. It provides a unique understanding of how all these stakeholders experience the Singapore MH services for adults with ID and their respective roles, as well as the relationships within and between the various groups of SUs and service providers. Negative public perceptions and stigma have an adverse impact on people with ID integrating into their community and there is a lack of focus on helping people with ID to have meaningful relationships and social interactions. Participants identified desirable attributes of SMHPs and recommended ways to provide the MH services. This chapter discusses the main findings and their implications for service delivery as well as recommendations for future research in Singapore.

Comparison of findings

There are similarities and differences that can be drawn from the accounts of the different groups of participants. All of the participants in the studies acknowledged the complexity of MH problems of people with ID and the high levels of emotional distress when they were first seen by MHPs. MMHPs and SMHPs spoke about the greater severity of MH problems and challenging behaviours in people with ID as described in the sub-themes *"comparison with general population" and "my work is challenging".* These were similarly reflected under the sub-themes with FCs *"not easy to take care of someone with behavioural problems"* where they shared information about their struggles in taking care of their relatives.

Research has shown that people with ID often seek MH services because of a psychiatric or behavioural crisis (Lunsky & Gracey, 2009) as reflected by the experiences of SUs under the themes *"awareness of mental health problems"* and *"sense of self"* regarding their high emotional distress during the initial period of treatment and admission. FCs shared their concerns about their relatives' poor emotional regulation that increased their care burden and high levels of caregiving stress. MMHPs described the lack of willingness to interact or work with this population because of their feelings of fear and uncertainty when managing the emotional distress in people with ID. On the other hand, SMHPs were more likely to take time to understand people with ID and focus on building trust with them. They reported more confidence in managing the emotional distress and challenging behaviours of people with ID using non-pharmacological interventions.

The societal stigma described by the participants in the current study has an impact on service provision, especially when working with FCs to integrate their relatives in the community. Both groups of MHP's acknowledged that public reaction has a negative impact on the opportunities for people with ID to participate and contribute within their communities as described in the sub-themes *"reaction from the public"* and *"the public just want to get away from them".* FCs similarly described their unwillingness to bring their relatives out in the community especially for those with more severe ID, MH and/or behavioural problems who require high levels of care in order to avoid dealing with negative public reactions. The experiences of SUs show that their interactions with their MHPs, family members and members of the community are influenced by stigmatising attitudes which could have a detrimental effect on their self-esteem and self-identity. All of the participants focused on improving the competency of people with ID to enter the workforce as a way to improve the public perception and respect of people with ID. SUs hoped that they can

engage in some form of work while FCs expressed their desire that their relatives can be accepted by the community when they enter the workforce. However, MHPs and FCs acknowledged that this takes a long while to reach public acceptance as people with ID can be viewed as 'dangerous' and unable to contribute to Singapore society. Those who are unable to work because of their severity of ID, MH and/or behavioural problems face more challenges with public acceptance and are not treated with respect which is highlighted in the experiences of FCs. Both groups of MHPs observed that the public would socially distance from people with ID or blame their FCs when their relatives became disruptive in public, which FCs similarly acknowledged under the master theme *"public reaction".*

Both groups of MHPs primarily used the bio-medical model as a way to treat and manage the MH problems of people with ID. Similarly, FCs reported being satisfied with this approach as described in the sub theme *"Bio-medical treatment approach"*. SUs also agreed with the use of psychotropic medication to treat their MH problems and primarily viewed their MH problems as a result of chemical imbalance in their brain. Only a minority of SUs were able to identify environmental or social factors that contribute to their emotional distress. FCs sometimes attributed the MH problems and challenging behaviours to the diagnoses of developmental disorders such as ASD and ID. Despite that, SMHPs advocated using non-pharmacological approaches that include FBA and PBS to train FCs and support staff to identify environmental triggers and use low arousal approaches to reduce the emotional distress in their relatives. Initially, the FCs were not aware of these non-pharmacological approaches and found them beneficial after learning the strategies to understand their relative better as a person. Additionally, they noticed a change in behaviour in their relatives after attending occupational therapy and were agreeable to reduce the dosage of medication. MMHPs lacking the knowledge of these approaches resort

to using restrictive practices such as restraint and medication which can escalate the emotional distress of people with ID as shared by a SU in the study.

MMHPs in chapter 4 were less likely to recommend people with ID for psychological interventions because they perceived that people with ID lack the cognitive ability to understand and make sense of their MH problems. This perceived low cognitive ability was similarly reflected in the themes of some of the medical SMHPs and FCs where they attributed people with ID lacking the capacity to engage constructively during psychological interventions. Similar themes found in the SUs highlighted they did not receive psychological intervention and had few opportunities to share about the impact of MH problems on their sense of self with the professional staff. The themes of SUs indicated that they were psychological affected by their MH problems and treatment, however they did not have access to psychological interventions to help them cope with their emotional distress. Non-medical SMHPs were more supportive in the use of psychological interventions for this population and were able to adapt the techniques to cater to their level of understanding. They were more receptive that people with ID should have access to psychological interventions and the themes of the SU similarly reflected that they could engage in introspection with additional support.

MHPs in both groups identified the importance of promoting choice and autonomy for people with ID which was something the SUs agreed on as well. The specialist MH ID service differs from mainstream services in that the specialist ID staff identify with the interests of people with ID and develop an individualised plan according to their needs. However, this was something not reflected in the themes of FCs. MHPs expressed the view that people with ID have the right to choose and have autonomy over their own lives but described the

challenges they faced when attempting to take into account the SUs' views. One of the challenges is that FCs often may not see the need to involve their relatives to have a say in their treatment, as such MHPs from both groups acquiesced with the decisions made by FCs albeit with concerns that the needs of FCs are prioritised against the wishes of their relatives with ID. This was also found in a review of studies conducted by Cannella et al. (2005) which found that people with ID had limited decision-making opportunities regarding their own health-related issues. MHPs in this study believe that the cultural context in Singapore could explain why they perceive FCs should make the decisions on their relative's behalf and that they may underestimate the cognitive ability of people with ID to understand their own health conditions. This differs from the findings of the SUs who demonstrated awareness of their MH conditions or emotional difficulties and their desire to have a greater autonomy over their lives. SUs spoke of a lack of empowerment during their hospital stay, the use of restraints to manage their emotional difficulties and their choices regarding treatment and discharge being ignored which may likely encourage passivity or challenging behaviour and affect their relationships with MHPs (Fish & Hatton, 2017).

Family involvement was considered important for all of the participants who perceived that family support and being discharged to their families' homes play a positive role in promoting better outcomes for people with ID, for example improving the accessibility of general services for people with ID so that they can remain engaged and be part of their community. Both groups of MHPs acknowledged the need to involve FCs during the treatment process of people with ID, however SMHPs reported higher frequencies and successes in working with FCs to address the MH problems of their relatives than MMHPs. This may likely be due to the different approaches that both groups of MHP adopt. MMHPs are more likely to work with FCs during the assessment phase to find out more about the

MH problems but work individually without the support of other professionals from different specialities to develop treatment plans. On the other hand, SMHPs work using a multi-disciplinary team approach that comprises of professionals from varying specialities, hence they have more resources and time to engage with the FCs from the start of the assessment phase to intervention and discharge process. FCs in the study were supported to be involved in the treatment process of their relative and felt that SMHPs consulted with them on every step of the treatment process. SUs who had the support of their FCs felt that they could turn to them for advice and emotional support which alleviated their distress whereas those without the support of their FCs found themselves isolated, lonely and with a sense of rejection. Therefore, MHPs consider the involvement of FCs during the treatment process may reduce the likelihood of SUs staying in an institutionalised setting and SMHPs are working to empower FCs to identify community resources that they can seek to help them manage the demands of care when their relatives are discharged home.

FCs and SUs differ in their views when it concerns relationships or social interactions. MHPs from both groups highlighted difficulties to address sexuality and intimacy when working with this client population because of a lack of support from family and support staff. The themes from FCs indicate that they do not prioritise this and may choose to avoid dealing with this issue, possibly due to their perceptions that people with ID are not competent or ready to have relationships with others. Although MHPs are supportive of working with FCs to address the sexuality and intimacy concerns that people with ID may experience, they are uncertain about how to advocate for SUs' rights especially when their FCs discourage intimate relationships. This is consistent with literature that found that although professional staff are open to discussing sexuality and intimate relationships, FCs are reluctant for people with ID to have intimate relationships although more accepting of them

forming non-intimate friendships (Evans et al., 2009). The lack of discussion of these relationship issues is not uncommon and it has been noted by other authors that people with ID are often restricted from exploring sexual intimacy and forming relationships with others (Alexander & Taylor Gomez, 2017). The desire to have relationships with others is universally found among people with ID and many aspire to get married and have a family (Healy et al., 2009). Cultural differences in Singapore whereby it is considered taboo to discuss sexuality and intimacy makes it different for MHPs to advocate the sexual rights of people with ID when working with FCs (Paulo et al., 2020). The themes in MMHPs also reveal the negative perception that people with ID are seen to increase the burden of cost for the state when they form families and have children, hence this may account for the reason why FCs are hesitant to explore these issues and rather focus on other issues, such as the employability of their relative in the community.

How do healthcare professionals in Singapore describe their experiences working with people with ID and MH problems?

The challenges of communicating with people with ID and understanding their MH issues reported by both MMHPs and SMHPs are consistent with other research findings (Araten-Bergman & Werner, 2017; Taggart et al., 2010; Werner & Araten-Bergman, 2017), suggesting that feelings of fear and uncertainty are caused by a lack of knowledge and training. Previous research studies highlight staff training and work experience as important mediators that improve the confidence of healthcare professionals and their attitudes towards people with ID which, in turn, can have an impact on service delivery (Bates et al., 2004; Costello et al., 2007). Having expertise and work experience allows SMHPs to feel

more confident and comfortable to develop trusting therapeutic relationships with people with ID when compared to MMHPs (Chapters 4 and 5). This was similarly shared by FCs who were dissatisfied with the mainstream MH services and perceived that MMHPs lack the necessary skills and expertise to address the MH problems of people with ID. FCs in Chapter 6 reported more satisfaction with specialist staff as they were said to take greater care and make efforts to understand SUs as individuals instead of merely focusing on their MH problems. Chapters 7 and 8, which reported on the views of SUs, confirm previous literature that indicates that the ability to build rapport and trust are qualities that people with ID look for in MHPs and that this has a positive impact on the treatment process and health outcomes (Bonell et al., 2012; Weise et al., 2018).

The delivery of specialist MH ID services differs from mainstream services in that they are inclined to have more multidisciplinary teamwork and collaboration with other MH professionals and stakeholders (including FCs and support staff in the community). However, the specialist MH ID service delivery is primarily situated in a tertiary hospital setting and MMHPs in Chapter 4 described a lack of involvement of specialist MH ID professionals in community mainstream MH services and having to manage the MH problems of people with ID on their own. This may affect the accessibility for people with ID seeking specialist MH ID services which may delay identification and treatment of MH problems. Hemmings et al. (2014) recommend MH services with SMHPs and MHPs working together in the community to meet the MH needs of people with ID. Singapore could consider such an approach and expand the specialist MH ID service into the community. This will require an increase in MHPs with appropriate qualities and attitudes to become specialised in working with this specific client population.

One of the roles of SMHPs is delivering training in non-pharmacological behavioural interventions to residential support staff and FCs to address the MH problems of people with ID, as highlighted in Chapter 5. The literature review in Chapter 2 suggests that effective educational and training approaches delivered by SMHPs can improve the attitudes of support staff which, in turn, may lead to a positive change in how support workers provide care in the community (Crickmore and Wray, 2009). A further role that can be recommended for SMHPs is that of advocate for people with ID to ensure appropriate access to relevant services.

Psychotropic medication was shown to be the treatment of choice to address the behaviours and/or MH problems of people with ID, confirming high prevalence use reported by other authors (Bowring et al., 2017) in the absence of evidence for efficacy in this client population (Brylewski & Duggan, 1999). Non-western countries such as Taiwan and Hong Kong found similar high trends of psychotropic medication usage among the elderly and females with ID (Hsu et al., 2014; Kwok et al., 2010).

The findings of the thesis indicate that restrictive practices were used to manage challenging behaviours in line with findings of another Singapore study that showed that ID professional staff in the social service sector employ similar restrictive practices and lack knowledge of alternative, non-restrictive practices (Manokara et al., 2018). It is recommended here that SMHPs track drug usage in the specialist MH ID service and introduce alternative treatment approaches such as PBS which has been shown to reduce the usage of medication and severity of challenging behaviours (Gerrard et al., 2019). Educational campaign programmes, for example the STOMP initiative in the UK (Branford et al., 2019; National Health Service England, 2016), could be adapted for a Singapore setting to educate different stakeholders

on the use of medication and promote non-restrictive practices as a more effective way to address the MH and/or behavioural problems of people with ID.

Both groups of MHPs expressed generally favourable attitudes to people with ID and MH problems, such as advocating for them to be a part of the community and working to increase their competency in order to have better job opportunities. SMHPs tried to promote SUs' autonomy through engaging them when planning activities and worked with FCs to facilitate successful discharge back into their communities. However, MHPs endorsed a number of negative perceptions of people with ID, such as the limited role people with ID should play in their MH treatment and being unsuitable candidates for psychological interventions because of their communication and cognitive limitations. Traditional psychotherapy models exclude people with ID on the basis of their low cognitive ability to understand and grasp the tenets of psychotherapeutic concepts, as mentioned by MMHPs in Chapter 4. However, Thomson and Johnson (2017) found that women with ID showed understanding of the therapeutic model and demonstrated that they were capable of learning and applying strategies to regulate their emotions. Adapted forms of CBT and dialectical behavioural therapy have shown promising results in reducing challenging behaviours and MH problems in people with ID (Brown et al., 2013; Hassiotis et al., 2013; Willner et al., 2013). Meta-synthesis and systematic reviews similarly show efficacy of CBT for treating mood disorders and anger management problems (Felce et al., 2015; Unwin et al., 2016; Vereenooghe & Langdon, 2013). It is noted that people with ID experience similar psychological issues such as trauma and grief (Hollins & Sinason, 2000) and the current findings suggest that SMHPs can do more to address misconceptions among MMHPs through training and supervision, such as training them to adapt the different therapeutic modalities when working with this population (Jahoda et al., 2017). Additionally, SMHPs can

work with other MMHPs to increase accessibility of psychological interventions as previous research indicates positive feedback from people with ID who have received psychological interventions (Lewis et al., 2016; MacMahon et al., 2015; Pert et al., 2013; Stenfert Kroese et al., 2016).

Both groups of MHPs acknowledge that the specialist MH ID service can be further improved to empower people with ID and provide more opportunities for them to have a say in how they lead their lives as was described in the sub themes *"level of autonomy"* and *"they should be given more choices".* It is noted that people with ID, especially those who receive inpatient treatment, face greater disempowerment due to segregation and limited opportunities for decision-making regarding their MH conditions. This is likely because people with ID are seen as 'vulnerable', also reported in the literature review in Chapter 2, and SMHPs described an imbalance of power or *"asymmetry in the decision making"* in the hospital setting as a barrier to SUs' choices to be taken into consideration. Therefore, it is recommended that HCPs find ways to support people with ID to make decisions which may further result in improving their self-confidence and self-esteem (Williams & Porter, 2017).

What are the implications of the current findings for the specialist MH ID service?

The findings from the thesis indicate that the specialist MH ID service has had a positive impact on the lives of people with ID and MH problems and FCs report higher satisfaction with this specialist service when compared to mainstream services. Thus, there is a continued need for a specialist MH ID service and implications for service delivery and training are discussed in this section.

Addressing stigma

The participants spoke about the stigma and discrimination that people with ID faces when accessing services or participate in the community. MHPs play an important role in addressing the stigma and find opportunities to collaborate with different organisations to improve the public perception of people with ID. This could include working with the government policy makers to develop appropriate clinical practice guidelines based on evidence-based findings. SMHPs can provide educational training to HCPs working in general mainstream healthcare services where they may come into contact with people with ID accessing their services. Additionally, SMHPs can work with FCs and SUs to develop coping strategies to deal with public stigma and improve the attitudes of support staff through training and consultation. Public educational campaigns that target to improve the public perception of people with ID could be developed with the involvement of SMHPs and government policy makers can tap on their expertise to develop new services or programmes to suit the needs of people with ID and their carers.

Early access and detection of MH problems

FCs in Chapter 6 reported that they seek specialist MH ID service when their relative's MH and/or behavioural problems become too difficult for them to be managed. MMHPs described that there is a lack of referral pathway for people with ID and are unaware about the types of cases that are appropriate for referral to specialist MH service. Hence, there is often a delay for people with ID to seek treatment early and more needs to be done to improve the accessibility of specialist MH ID service. Public resources could be targeted to reduce the barriers for people with ID to seek specialist MH services. Policy makers should plan for the specialist MH ID service to expand while embedded in the community or within mainstream services where MHCPs and MMHPs can refer after carrying out a screening

assessment. In addition, collaboration between SMHPs and other HCPs including MHPs through providing supervision and training as well as better coordination with social services are recommended. For example, SMHPs can work with mainstream services to reduce the use of psychotropic medication and train FCs and support staff in non-pharmacological interventions to reduce the severity of challenging behaviours. Additionally, SMHPs can collaborate with social services to advocate for their rights, such as promoting a greater presence in the community for people with ID through participation in leisure activities, employment and relationships, including intimate ones.

Recruiting suitable specialised healthcare professionals

SMHPs reported that they did not set out to specialise in the ID field and had initial feelings of fear and trepidation when working with people with ID and MH problems before gaining more confidence as a result of their work experience. Thus, more efforts could be made to encourage healthcare students to consider working in this field upon graduation. Education and knowledge of ID introduced in undergraduate studies have been found to improve attitudes to people with ID among healthcare students (Kritsotakis et al., 2017; Sinai et al., 2013; Temple & Mordoch, 2012). Additional resources such as work placements could be introduced to provide healthcare students in Singapore with a sense of what it is like to work with people with ID and help them to decide whether to specialise in the MH ID field.

The findings of the thesis can be used as a guide for managers to develop a set of desirable qualities or a competency checklist to assess the suitability of job candidates wishing to specialise in the field of MH and ID. In Singapore, there is a residency programme for newly qualified medical staff whereby they are rotated to work with people with ID and MH problems to expand their work experience and knowledge. This could be adapted to include

non-medical HCPs undergoing similar work rotation to improve their expertise and encourage them to consider working in this specialist field. Organisational support by means of hospital policy and management may also improve the manpower resources and retention of SMHPs, for example allowing them to take a longer time to assess and review the MH problems of people with ID and having available funding for them to attend ID-related research conferences and/or attend postgraduate course relevant to the ID field. Having a clinician support group for MMHPs and SMHPs can contribute to skills developments and sharing of work experiences by SMPHs which may encourage more MMHPs to consider acquiring further specialisation and work with this population.

Increasing training and competency

Most of the SMHPs did not receive professional training in the field of ID and acquire their skills through on-the-job work and contact with people with ID. As such, there is a possibility that they may not receive theoretical knowledge and understanding of the MH needs of people with ID and the issues they face. This could affect the quality of service provision in the long term and policy makers should consider providing financial grants or scholarships for SMHPs to receive accredited postgraduate training in ID and MH. Having qualified training and knowledge could lead to an improvement of evidence-based practices and guidelines for the service and SMHPs could impart their knowledge to other MMHPs or newly joined SMHPs. In addition, SMHPs would have a better knowledge and understanding of non-pharmacological interventions and provide guidance to other MHPs on how to adapt their techniques and strategies when working with people with ID. This would encourage MHPs to consider using psychological interventions, such as CBT rather than solely rely on psychotropic medication, thereby changing their views that people with ID can benefit from engaging in psychological interventions.

Working with people with ID

These results have highlighted cultural differences that both MMHPs and SMHPs in Singapore need to consider when working with people with ID and MH problems, for example identifying religious influences, support and resources available for the SU, the role of the FCs and understanding their needs, as they play a significant role in the treatment of and discharge outcomes for their relatives. Building a trusting working relationship with FCs can start with understanding their concerns and the challenges they face in taking care of their relatives. Providing training in non-pharmacological interventions to increase their self-efficacy and confidence in managing their relative's behaviours could lead to a discussion about creating opportunities for their relative's social integration. Having opportunities to work with people with ID and their FCs in their own neighbourhood offers a more naturalistic setting that may help to address the challenges and anxieties regarding bringing them out in the public and FCs can benefit from learning coping strategies to deal with the public reaction.

The findings of the study reveal that people with ID experience high levels of emotional distress when they first encounter MH services. Hence, both groups of MHP should be equipped with strategies to calm SUs and reduce the triggers which may arouse them. Having the knowledge of the behaviour management strategies that focus on the avoidance of confrontation and reducing demands or requests can reduce potential points of conflict around the person with ID (McDonnell, 2010). Making modifications to the environmental setting in the hospital, reducing the frequency of restrictive practices and increasing engagement between the staff and the person with ID can reduce the challenging behaviours and improve their quality of life (Mackenzie-Davies & Hardy, 2010). Therefore,

MHPs should take time to understand the person with ID better and strive to build trust and rapport with them rather than focus on treating the symptomology of their MH problems.

Working with people with ID also includes the support of community service providers in supported employment agencies and residential institutions for people with ID and MH problems. SMHPs can work with these stakeholders to develop inclusive practices within their own organisations to promote choice and autonomy in people with ID, for example encouraging the SUs of these services to share their views with staff and involve them when it comes to planning leisure activities. SMHPs can also work with FCs to promote choice and autonomy for their relatives especially when it comes to future care planning. FCs and support staff can learn to adapt communication techniques to encourage people with ID to express their views and make decisions about how they wish to lead their lives. In addition, they can also encourage their relatives to receive psychological interventions and work with the MHPs to improve their relative's sense of self and self-identity. Community service providers can provide resources for people with ID to have a peer support group where a trained MHP or professional staff can facilitate people with ID to share about their feelings to others in a safe space and learn strategies to help them cope with their feelings and MH problems. There can be further opportunities for SMHPs to train support staff in the residential setting to become para counsellors to provide emotional support to people with ID through active listening and finding activities to keep them engaged.

The specialist MH ID service aims to integrate people with ID and MH problems in the community through employment. There are ways in which people with ID and MH problems can participate such as having social interactions with members of the public through engaging in leisure activities. SMHPs could collaborate with FCs to develop short-term goals

for their relative with ID to develop social networks and friendships. Research has shown that social skills training programmes has helped people with ID to form meaningful relationships that lead increasing in their social network and going on dates with other people (Ward et al., 2013). This is something that the specialist MH ID service could consider and work with relevant community service providers to encourage more social interactions between the public and people with ID.

Recommendations for future research

One of the limitations of this thesis is that the results cannot be generalised to all MHPs in Singapore. Thus, it is imperative to explore the experiences of other groups of professional staff working with people with ID and MH problems in different settings, such as support staff in supported employment services, to have a more comprehensive understanding of how people with ID and MH problems are supported in the community following their discharge from the specialist MH ID service. Employers providing supported employment can be interviewed to explore their views about employability of people with ID and MH problems. Moreover, the views of generic HCPs providing general health services should be considered to understand the support and training they require to treat people with ID and MH problems.

The participants in this thesis spoke about public stigma and prejudice faced by people with ID and MH problems. Thus, further research could use validated measures to supplement the findings of this thesis and examine the differences in the attitudes between the public and HCPs in Singapore. Boo and Nie (2017) validated the Attitudes towards Intellectual Disability questionnaire (ATTID; Morin et al., 2013) on a Singapore population and

discovered a three-factor structure (instead of five) which suggests cultural differences when compared with a western population. Other research with FCs could examine how they cope with their caregiving responsibilities using standardised measures such as the Way of Coping Questionnaire (Rexrode et al., 2008).

There has as yet been no longitudinal studies to examine the outcomes of people with ID accessing specialist MH ID services in Singapore. Future research could track people with ID when they first access the service and at various follow-ups as part of service evaluation research to measure the impact of this service. Other suggestions for research include examining ways to adapt therapeutic interventions such as CBT (Jahoda et al., 2017) and the outcomes of people with ID in a non-western population after receiving these interventions.

People with ID can be involved as co-researchers during all stages of research development (Strnadova & Walmsley, 2018) to increase the involvement of people with ID in disability-related research in Singapore and encourage them to share their views on issues that are important to them, such as sexuality and voting participation. They can also provide feedback about improving accessibility of mainstream general health services and further research can explore the best ways in which to involve them when training HCPs and MHPs.

Summary

This thesis used different qualitative methodologies to explore the experiences of sample populations (MHPs, FCs and SUs) to attempt to fill the existing gap of knowledge in the literature as reflected in Chapter 1 (Introduction). The experiences of different groups of the

population added a detailed insight into the service delivery of a specialist MH ID service in Singapore.

Study 1 (Chapter 4) explored the experiences of MMHPs working with people with ID and MH problems. The findings are consistent with existing literature, that is, this group face challenges working with this population due to poor knowledge and work experience. Nonetheless, the study identifies that MMHPs are keen to receive additional training and supervision to improve their confidence to manage the MH problems of people with ID.

Study 2 (Chapter 5) explored the experiences of SMHPs working with people with ID and MH problems. The findings provided a unique insight into their specialised roles and their significant focus on involving FCs during the treatment process. SMHPs are interested in building genuine therapeutic relationships with people with ID and want to provide training to FCs and support staff in using non-pharmacological approaches to manage the MH problems of people with ID.

Study 3 (Chapter 6) describes the experiences of FCs of people with ID and MH problem and the challenges they encounter managing the behavioural and MH problems of their relatives with ID. They found it beneficial to receive specialist MH ID services and were satisfied with the treatment of their relative and the support received by the SMHPs.

Study 4 (Chapter 7) set out to explore the experiences of ISUs receiving inpatient specialist MH ID services. The findings corroborate previous research that people with ID have some understanding of their MH conditions, face discrimination and stigma in the community and are sometimes disempowered by their FCs as well as by professionals when receiving inpatient treatment.

Study 5 (Chapter 8) expands on the first-hand experiences of people with ID and MH problems by interviewing OSUs receiving outpatient specialist MH ID services. This group had more involvement in the community through supported employment and reported that they received support from their family and friends to help them deal with their MH problems.

The current research has identified the efforts made by the specialist MH ID service in Singapore to improve the lives of people with ID and MH problems. The qualitative data reported in this thesis has facilitated a deeper understanding of the experiences of different stakeholders in Singapore concerned with the MH problems of people with ID.

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Appendices

Appendix 1: Information Sheet and Informed Consent Form (Mental Health Professionals)

(Links to Chapter 4 and 5)

1. Study Information

Protocol Title:

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

Principal Investigator & Contact Details:

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Clinical Psychologist
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Co-Investigator:

Mr Jonathan Ee

Doctoral Researcher
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Study Sponsor:

University of Birmingham

2. Purpose of the Research Study

You are invited to participate in a research study. It is important to us that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign this informed consent form. You will be given a copy of this consent form to take home with you.

This study is carried out to explore the attitudes of healthcare professionals towards adults with neurodevelopmental disorders and mental illness in Singapore. We hope to learn about the

experiences of healthcare professionals working with this population as they navigate the mental health services with their family members.

You are invited because you are:

(1) a healthcare professional involved in the care of people with mental illness and/or with co-morbid neurodevelopmental disorders

This study will recruit around a range of 16 - 24 healthcare professionals from Institute of Mental Health over a period of nine months.

3. What procedures will be followed in this study

If you take part in this study, you will be asked to attend an interview session with the interviewer (Co-Investigator). Your participation in the study will last up to 60 minutes. The interview will be audio taped and destroyed after the research study.

If you agree to take part in this study, the following will happen to you:

Schedule of visits and procedures

Visit 1: Interview session with the interviewer consisting of up to 60 minutes at a private room in IMH. The interview will be audio-recorded which will be transcribed for the purpose of analysis. The audio recordings will be destroyed after the study has ended.

A written summary of the findings of the questionnaire is available upon request after the study has ended via soft copy. You may wish to leave your email address with the interviewer if you are interested to receive a copy.

4. Your Responsibilities in This Study

If you agree to participate in this study, you should follow the advice given to you by the study team. You should:

- Be prepared to visit the hospital for at least one session and undergo all the procedures that are outlined above.
- Keep your study appointments. If it is necessary to miss an appointment, please contact the study staff to reschedule as soon as you know you will miss the appointment.
- Inform the Principal Investigator as soon as possible about any possible emotional distress that you may have experienced.

5. Possible Risks and Side Effects

In any unlikely event that you experience emotional distress as a result of sharing about your experiences, you should:

- May wish to withdraw during the interview.
- Inform the Principal Investigator who will refer you for staff counselling or emotional support within IMH.

6. Possible Benefits from Participating in the Study

There is no known benefit from participation in this study. Talking about your experiences may be a cathartic process and you may have a deeper understanding of own experiences better. In addition, your participation may contribute to the understanding of healthcare professionals' attitudes towards individuals with neurodevelopmental disorders and mental illness, which could increase the knowledge in this field. These research findings may lead to organisational and policy improvements for the hospital's management and Singapore regarding services for individuals with neurodevelopmental disorders.

7. Alternatives to Participation

It will not impact your work in your department should you choose not to take part in this study.

8. Costs & Payments if Participating in the Study

You will be reimbursed for your time, inconvenience and transportation costs as follows:

- If you attend the interview, you will be paid $20 cash voucher

9. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator. Confidentiality may need to be breached in order to communicate any safety concerns to appropriate services to protect the safety and wellbeing of you, your family member or other people.

You will be required to inform the Principal Investigator if you wish to withdraw from the study after the interview. The data will not be used and will be discarded.

Your doctor, the Investigator and/or the Sponsor of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you *(or your legally acceptable representative, if relevant*) will be informed in a timely manner by the Principal Investigator or his/her representative.

10. Compensation for Injury

If you follow the directions of the doctors in charge of this study and you are physically injured due to the trial substance or procedure given under the plan for this study, the National Clinical Trial Policy will pay the medical expenses for the treatment of that injury.

Payment for management of the normally expected consequences of your treatment will not be provided by IMH.

IMH without legal commitment will compensate you for the injuries arising from your participation in

the study without you having to prove IMH is at fault. There are however conditions and limitations to the extent of compensation provided. You may wish to discuss this with your Principal Investigator

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

11. Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, the Sponsoring company, Regulatory Agencies and NHG Domain Specific Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you (*or your legally acceptable representative, if relevant*) are authorizing (i) collection, access to, use and storage of your "Personal Data", and (ii) disclosure to authorised service providers and relevant third parties.

"Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. This includes medical conditions, medication, investigations and treatment history.

Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected will be anonymized and entered into the Case Report Forms. These anonymized data are the property of University of Birmingham and Institute of Mental Health. In the event of any publication regarding this study, your identity will remain confidential.

12. Whom To Contact if You Have Questions

If you have questions about this research study, you may contact the Principal Investigator, Ms Lim Jan Mei *(* [redacted] *) or* the Co-Investigator, Mr Jonathan Ee, at [redacted]

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266. You can also find more information about participating in clinical research, the NHG Domain Specific Review Board and its review processes at www.research.nhg.com.sg.

If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

CONSENT FORM

Protocol Title:

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

Principal Investigator & Contact Details:

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I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction. I have also been informed and understood the alternative treatments or procedures available and their possible benefits and risks.

_____ _____

Name of Participant Signature Date

Translator Information

The study has been explained to the participant / legally acceptable representative in

_____ by _____

<insert language > *<insert name of translator >*

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of his / her participation in the study.

_____		_____
Name of Investigator / Person administering consent	Signature	Date

Appendix 2: Interview Schedule (Mental Health Professionals) (Links to Chapter 4 and 5)

Thank you for agreeing to be interviewed for this study. Your contributions will be very valuable. This interview will last up to an hour and I am interested in understanding your experiences of working with people with intellectual disabilities and mental health problems.

1. What is it like working with people with intellectual disabilities and mental health problems?
    a. *Prompt: - Can you share with me some experiences of your typical work day?*
    - How did you find yourself working in this field?
    - What has been challenging? What has been easy for you?

2. What makes someone suitable to work with this people with intellectual disabilities and mental health problems?
    a. *Prompt: - What qualities or attributes are needed to be a good worker?*
    - What do people need to know before considering working in this field?

3. How do you think mainstream healthcare workers/professional staff react when working with individuals with intellectual disabilities and mental health problems?
    a. *Prompt: - What are they thinking, feeling or doing when working with this population?*
    - Are there times when their reactions have an impact on their work?
    E.g Can you think of any positive or negative reactions or experiences?

4. When you are working with people with intellectual disabilities and mental health problems, who do you mostly work with/talk to? Why do you think that is?
    a. *Prompt: - the individual client/patient alone? With family members? Professional staff from different organisations?*

5. Do you think there is a difference in how people with intellectual disabilities and mental health problems are being cared for by professional staffs and family members, and if so what and why?
    a. *Prompt: - exploration of goals, attitudes, beliefs, values?*

6. Are there any differences in how you manage the mental health problems of people with and without intellectual disabilities and if so what and why?

a. *Prompt: - What are the differences and similarities in treatment approaches?*

7. What do you think about involving individuals with intellectual disabilities and mental health problems having a say about how they wish to manage their health?
    a. *Prompt: - Do you think they can make choices about their health or what they want in life? Why is that so?*
        – What happens when they state a preference of a particular treatment approach / modality?

8. What do you think about giving individuals with intellectual disabilities and mental health problems a say in their own care management?
    a. *Prompt: - Do you think they can make choices about their health or what they want in life and if so, are there any limits to this?*
        - What happens when they disagree or refuses treatment (e.g medication)?
        - What do you do when they exhibit challenging behaviours?

9. What do the people and family members find helpful when engaging with your services?
    a. *Prompt: - Can you share any experiences of working with people with mental health problems and/or neurodevelopmental disorders or family members?*
        - Are there any examples of where you have felt you've made a positive difference?

10. What could help you do to improve your clinical practice?
    a. *Prompt: - Training, experience, supervision, support, time or additional resources*
        - Why is this important?

11. How can healthcare professionals improve the quality of life in individuals with intellectual disabilities and mental health problems?
    a. *Prompt: - What other services do you hope would be available to them?*

12. Are there any other things you'd like to say?

Thank you for your time etc. Ask if they would like to be sent a summary of the results.

Appendix 3: Participant Demographic Sheet (Mental Health Professionals) (Links to Chapter 4 and 5)

Demographic form

Participant No *(please do not fill in):* _____

Name: _____ Age: _____

Gender: _____ Ethnicity: Chinese /Malay / Indian / Other*: _____

Current Occupation: _____

No of years working since qualified: _____

No of years working with individuals with neurodevelopmental disabilities: _____

Type of training or experience related to understanding and/or working with people with neurodevelopmental disorders (List the significant courses):

1. Course Name: _____
    a. Level of training: **Basic Training** (i.e.IMH ID Nursing) / **Intermediate** (i.e. Master Degree, attachment training, on the job training) / **Advanced** (i.e. Professional specialization) /Others: _____
    b. No of hours: _____
2. Course Name: _____
    a. Level of training**: Basic Training** (i.e.IMH ID Nursing) / **Intermediate (i**.e. Master Degree, attachment training, on the job training) / **Advanced** (i.e. Professional specialization) /Others: _____
    b. No of hours: _____
3. Course Name: _____
    a. Level of training**: Basic Training** (i.e.IMH ID Nursing) / **Intermediate (i**.e. Master Degree, attachment training, on the job training) / **Advanced** (i.e. Professional specialization) /Others: _____
    b. No of hours: _____

Appendix 4: Example of a worked interview transcript (MMHP) (Links to Chapter 4)

Initial Codes	Original Transcript	Exploratory Comments
	I: Thank you for joining the study. Can you share with me what it is like, what is your experience like working with someone who has mental health problems? general mental health?	
	D: You mean, the patients?	
	I: Yeah, what is your experience working with them?	
Variety of severity of people with ID seen at mainstream psych services (1)	D: I think it depends on the severity of their ID. Some are quite alright and they do not have any much of an issue, no major behavioural problems and you can still communicate with some of them and it's not so difficult like in terms of interaction with them. However, some can be quite severe, erm they have a lot of behavioural problems...yes they can be quite distressing for the family also	People with ID seek mainstream psychiatric services at - Wide range of problems - Often sought help when the issues/problems become distressing for family
	I: What are some of the challenges that you faced working with this group of people?	Impact of care burden on family members -> experienced negative emotions?
People with ID seek treatment when it becomes distressing for family (2) Difficulties in conducting assessment (3)	D: They are a few...erm…one of them would be communication difficulties. Yeah, you do not know what's in their mind. They can't communicate, so when they don't feel comfortable or they feel distress, they are not able to tell why they are feeling so. So a lot of times when they present with behavioural problems because of their distress, we don't really know what is going on, from their own perspectives, a lot of times we have to rely on their caregivers, observations, what could be the possible triggers and things like that…yeah	Main challenge is communicating with people with ID - Difficulty to carry out assessment Use of alternative strategies for assessment -> Relies on secondary input, observations
	I: So with people with general mental health, they sometimes come in with family members?	
Difficulties in communicating with people with ID (4) Using alternative techniques for assessment (5)	D: Yeah…actually majority of them come with family members, unless those maybe borderline or very mild ID, they can still come and tell you about their problems and then that's okay	More severe -> family members are involved during the first visit
	I: In the general population, those with mental health problems, what has been easy working with this group of people?	
Family members are	D: Easy part? (Thinking) I think if there is someone present like caregivers present during	

involved during the consultation (6) Obtaining secondary information from caregivers is easier (7) Difficulties in engaging patients with more severe ID (8) Require more time to establish therapeutic relationship (9) People with general MH are easier to build rapport (10) People with severe MH may exhibit aggressive behaviours when relapsed (11) Accuracy of information is also important when working with people with MH problems (12) Lack of time in the clinic to hear concerns from family members for people with MH problems (13) Strategies that healthcare professionals take to spend more time	the assessment, then it is easier for us to find out what is going on. If not then, I think it is quite challenging. I: How about like in terms of building rapport or in terms of working with this group of people, how is your experience like? D: Yeah, I guess if it's really mild or borderline IQ, you can still build rapport with them without much of a problem but if it's quite a moderate to severe ID, then it's quite difficult. You may have to take some time to build rapport. Or you may have difficulties also without building about to build rapport also I: Then with people with general mental health problems, when you worked with them, how easy or difficulty is it when you are building rapport? D: Building rapport with them generally is quite okay, not of a major issue unless some people with personality problems or when patients with severe mental illness relapsed, then sometimes it can be an issue. They can turn violent suddenly in the clinic sometimes. I: So for those people with normal IQ with mental health problems, do they usually come to your clinic alone or? D: It's a mixture, can be alone or with caregivers I: Which one would be challenging for you? If they come alone or with caregivers? D: I guess sometimes if they come alone, we only can rely on what they tell you...don't know how true it is (laughs)...and we don't get corroborative history from family members…sometimes what they tell you is totally different from what family member experience at home. So they can be a challenge. Of course when family members are here, they also want to talk to you. Sometimes, the duration of time allowed per patient in the clinic, it can be quite challenging. You need more time, and a lot of times, we don't get the extra time. Because we don't know sometimes they want to come and talk to you and we are only allowed to have 10 minutes per patient, yeah that can be challenging I: In that scenario if more time is required, how would you manage?	Importance of family members to be involved in providing history details of the patient Difficulties establishing rapport with moderate to severe people with ID ➔ Communication issues? Lack of time to build rapport Easier to build rapport for people with MH problems Severity of MH illness may prove challenging to build rapport ➔ Especially when they experience relapse and exhibit challenging behaviours Lack of corroborative history from family members to confirm pt's MH problems Lack of time engaging with family members to address their concerns

during consultation (14)	D: Sometimes I think if it is really necessary to spend this time with caregivers, I will still spend extra, sometimes it may take more than 10 minutes, even up to 20 minutes sometimes. So unfortunately, the other patients would have to wait and some of them would not be happy. So if I know that the patient or the caregivers want to spend more time, maybe next time I would ask the staff to give me more time if I know in advance. Because some patient would spend more than 10 minutes talking to me I: Moving on, working with people with ID, let's say for a new professional staff, what qualities or attributes would someone need to have so that they can work with this group of people? People with ID and mental health problems?	Healthcare professionals acknowledged the importance of spending extra time with family members -> builds rapport? Understand their needs better? Or provide a listening ear?
Attributes of patience (15) Prior training & exposure in working with this population (16) Importance of patience (17) Behavioural intervention is main focus of treatment (18) Have attachment to observe how others work with people with ID (19) Challenging and difficult for mainstream worker to manage people with ID (20)	D: I see. I think a lot of patience. Because it is not easy to communicate with them, try to understand what's going on and manage the behavioural issues. You need a lot of patience and kind heart, big heart (laughter). Yeah, I also think they need to have some training to work with ID population, how to manage patients with ID. I: We will talk about the training part later. What kind of patience is required when working with this group of people? Are there any things that require more patience? D: For example, first of all, communication, communicating with them takes longer time maybe and also, managing their behavioural issues. It is not something that you can treat immediately, yeah maybe medication can help a bit but majority still depends on a lot on behavioural modifications. It takes quite time consuming also I: For someone who is waiting this field of working with people with ID, what do they need to consider first? To know that they are suitable to work with this group of people? D: Yeah erm...maybe they can speak to someone who is already in this field who had experience, and maybe they can have some attachment to observe what kind of things they would have to do in the future if they join. I: Are there any areas do you think they need to be aware of when they consider joining and working with this people? D: Erh..consider the challenges of managing patients' with ID I: So what do you think mainstream healthcare professionals would react when they see a patient with ID and mental health problems, when they work with this group of people? For example, they see them in the emergency department, in the mainstream	Importance to have patience for communication -> Need to spend time understand people with ID and carrying our behavioural interventions Main focus of treatment is behavioural interventions Intensive resources to carry out behavioural interventions, take time for interventions to be consistency Medication -> How can they help? Need to have passion first? Prior attachment or volunteering experience to have a understanding of people with ID before joining

	setting. How would they react?	
Not fully understand the issues due to lack of time (22) Fear that the people with ID would become violent (23) Feelings of scared (24) Feels frustrated when they can't communicate with people with ID (25) Lack willingness to work with people with ID (26) Different to treat people with ID when they can't communicate and find out the issues (27)	D: If they do not have much experience, it can be quite difficult and challenging. I think it depends on the setting also, if it is at the emergency room, then a lot of times the doctors are rushed for time and they do not have a lot of time to spend with the patient and relatives, so I guess there is a pressure of time and they may not be able to build a lot of rapport or take so much information from the family or the patients. So a lot of time is quick assessment and maybe they don't understand what is going on also because their role is to see whether there is a need to admit or not to admit to hospital, so it would be a very quick and not thorough assessment, I believe in a busy setting and sometimes if they are violent, it can quite scary as well for them. Yeah for the doctors and nurses also or anyone who has not much experience dealing with this group of people. I: How would they feel when they work? D: I think it can be...I think they would feel quite scared to be honest if they are not experienced and the patient is violent and all that…They would feel scared... I: Is there any thoughts they would think or go through their mind when they work with this group of people? What would they be thinking? D: Erm...I guess depends on individual, their personality also plays a role. Some of them would feel that they would have to waste so much time finding out what is going on and since the patient cannot communicate, some of them...they would not be bother to find out more from the patient also and they would probably get someone to assess and all that, that is one thing. Another thing is fear for their own safety, because it has happened before, patient who suddenly turned violent in the ward and hurt the staff. I: Does the way that they feel and the way that they think, are there times where these will impact the level of service that they provide? D: Yeah I think definitely, definitely if you can't find out, if you can't communicate, it you can't find out what's really happening with the patient, then you wouldn't be able to treat them properly. *(Transcript continues on)*	Main challenge of working with ID -> pressure of time and lack understanding of the person with ID due to difficulty communicating and building rapport Unsure of whether to treat or refer to specialised services Perception that people with ID are violent -> Fearful that the healthcare professionals may experience aggressive behaviour and lacked skills to manage them Scared feelings -> Have initial fear and negative stereotypes before working with people with ID? Feels like a waste of time -> Negative feelings of frustration? Not engaging with the patient with ID to explore their needs Not willing to work with them, finds that their workload may become too difficult Lack understanding of patient's issues would lead to difficulty in carrying out treatment

Appendix 4 (Continued) – Example of a worked interview transcript (MMHP) (Link to Chapter 4)

Theme 1: People with ID seeking mainstream mental health services

- **Sub-theme: Factors that led them to seek services**
    - Variety of severity of people with ID seen at mainstream psych services (1)
    - People with ID seek treatment when it becomes distressing for family (2)
    - Family would seek treatment when they can't manage the behaviours (36)
    - May seek psychiatric services for social needs e.g finding employment (37)
    - Challenges for people with ID to access specialised services (54)
    - How people with ID access community psychiatric services (34)
    - Some fell through the cracks due to strict inclusion criteria (59)
- **Sub-theme: People of ID found services helpful**
    - Improvement in MH symptoms (48)
    - Listening ear for family members (49)
    - Learning communication skills and behavioural management from mainstream professionals (50)
- Sub-theme: Differences in experiences between working with people with MH vs people with ID
    - People with general MH are easier to build rapport (10)
    - People with severe MH may exhibit aggressive behaviours when relapsed (11)
    - People with MH problems are likely can communicate their differences (33)
    - Accuracy of information is also important when working with people with MH problems (12)
    - Lack of time in the clinic to hear concerns from family members for people with MH problems (13)
    - Similarities in MH problems that healthcare professionals see in both groups (32)

Theme 2: What is it like for mainstream professionals working with people with ID?

- ***Sub-theme: Challenges working with people with ID***
    - Difficulties in conducting assessment (3)
    - Difficulties in communicating with people with ID (4)
    - Difficulties in engaging patients with more severe ID (8)
    - Require more time to establish therapeutic relationship (9)
    - Different to treat people with ID when they can't communicate and find out the issues (27)
    - Lack knowledge in identifying the triggers for the behaviours (28)
    - Medication is usually given without taking time to find out the triggers (29)
    - Not fully understand the issues due to lack of time (22)
    - Understanding what normal or abnormal behavioural reactions are (52)
    - Challenging and difficult for mainstream worker to manage people with ID (20)

- **Sub-theme: Strategies that mainstream healthcare professionals use to overcome the challenges**
    - Using alternative techniques for assessment (5)
    - Family members are involved during the consultation (6)
    - Obtaining secondary information from caregivers is easier (7)
    - Strategies that healthcare professionals take to spend more time during consultation (14)
    - Behavioural intervention is main focus of treatment (18)

- **Sub-theme: Recommendations for mainstream healthcare professionals to improve their work and interactions with people of ID**
    - Examples of training given to professional staffs (31)
    - Examples of the needs that people with ID require from healthcare professionals (35)
    - Examples of training that focused on behavioural assessment and intervention (51)
    - Basic training for mainstream professionals (55)

- Mainstream professionals come in contact with people with ID (56)
- Observations of other healthcare professionals working with people with ID (58)

Theme 3: Emotional reactions that healthcare professionals experience

- Fear that the people with ID would become violent (23)
- Feelings of scared (24)
- Feels frustrated when they can't communicate with people with ID (25)
- Lack willingness to work with people with ID (26)
- Prefers people with ID to be managed by specialised team (53)
- Mainstream professionals are uncertain in their competency (57)
- Lack of willingness to work with people with behavioural issues (60)

Theme 4: Quality attributes of ideal healthcare professional

- Attributes of patience (15)
- Prior training & exposure in working with this population (16)
- Importance of patience (17)
- Have attachment to observe how others work with people with ID (19)

Theme 5: Involvement of people with ID to make decisions related to their care

- Consider involving them when they are able to communicate (38)
- Importance to listen to the views of people with ID regarding their care (39)
- Needs to assess whether they understand their own treatment process (40)
- Family members are alternatives to engage when people with ID are not competent (41)
- Assessment of competency to understand their condition (42)
- Difficulty to carry out the wishes of people with ID (43)
- Healthcare professionals overwrite the person with ID's decisions (44)
- Institutionalisation as a last resort (45)
- Involvement of family members to facilitate people with ID to make decisions (46)
- Important that the people with ID's wishes are respected (47)

Theme 6: Challenges that people with ID faced in the community

- Lack of job opportunities for people with ID (61)
- Negative stereotypes from potential employers (62)
- Difficulties faced at work (63)
- Difficulties with interpersonal relationships (64)
- Perceives that people with higher severity of ID have difficulties having meaningful relationships (65)
- Negative stigma and discrimination from public (66)
- Perceived public shame towards people with ID and MH problems (67)

Appendix 5: Table of themes for all MMHPs (Links to Chapter 4)

Main Theme	Sub Themes	MMHP	Examples of quotes
Working with people with ID	**1. Comparison with general population** - Difficulties to understand them, poor engagement - Needing more time - Difficulty understanding mental health issues - Obtaining information from family members	1, 2, 3, 4, 5, 7, 8	**MMHP 1:** "I think if there is someone present like caregivers present during the assessment, then it is easier for us to find out what is going on. If not then, I think it is quite challenging." **MMHP 2:** "…if let say we cannot get much from the patients him or herself right so we can get the history from the family members because they are the ones who observe the patients in the community." **MMHP 3:** "...a lot of them present with problem behaviours that the caregiver cannot manage… In a lot of people with ID, especially those with more severe form, have verbal deficits. The manifestation seems to be different as well. Where someone who is depressed in the non ID, general population, they will be more restricted and their affect appears to be low and that could be the case with ID but it's more irritable." **MMHP 4:** "it is co-morbid with any form of psychosis, then you don't know what the triggers are…it's very difficult to monitor that kind of environment and the triggers."
	2. Emotional Reactions when providing services - Fear that they will become violent - Feelings of frustration regarding slow recovery	1, 2, 3, 4, 7	**MMHP 1: "**I think they would feel quite scared to be honest if they are not experienced and the patient is violent and all that" **MMHP 2:** "And it is very difficult to communicate with people intellectual

	- Unsure how to react - Unwillingness to work with them - Emotional reactions towards use of restraints		disabilities at first. So that could be quite frustrating. Because you don't know how to tell them, what not to do and you don't know what the cause…" **MMHP 4:** "...I just put them somewhere, placed them and the person would just stay put...I mean this would be after everything has done and nothing seem to work, and this is just a last resort already...yeah but obviously before that, probably can imagine them being helpless..." **MMHP 7:** "I already highlighted the feelings of the first group of people: confused, scared, not sure. I think the psychiatric doctors and nurses might feel a little bit anxious so anxiety is definitely there but maybe feeling unsure as well because they don't have a long-term relationship or the rapport or they don't know the profile of the person."
Perceptions of people with ID	**1. Level of autonomy** - Difficult to carry out the wishes of people with ID - Healthcare professionals mainly consult and discuss with family members - Family members consenting on their behalf to treatment - Denied opportunities to have meaningful lives - Healthcare professionals 'fixing' the problems - Unsuitable candidates	1, 2, 3, 4, 5, 8	**MMHP 2**: "If the family don't want to take them back, then there is no choice. They need to go somewhere else. We have to convince the patients to go to other stepdown care. Or what I can do is to convince the family members." **MMHP 3:** "I think it's more like paternalistic…Let me fix it for you, do all these for you.. You should do this and that. Are we considering their interest and what they would like. So i think the view is more like you need help, we will help you because you can't help yourself. We're not really empowering but we're making the choices for them.." **MMHP 4:** "I guess it would be easy to

	for psychotherapy		assume that the person cannot control their...again it's their disability..." **MMHP 4:** "….It's very easy to assume that the person is disabled and unable...cannot do this, cannot do that and all other stuffs." **MMHP 5:** "…so typically therapy ends up working with caregivers more than with the clients themselves."
	2. Reaction from the public - Blaming/ not blaming people with ID for their challenging behaviours - Unable to have employment or social opportunities	1, 2, 3, 5, 6, 8	**MMHP 1:** "a few of them can have meaningful relationships with people also, especially those with borderline to mild cases, but the moderate to severe ones probably would have difficulties....very likely, cannot have meaningful relationships with people and the public would tend to stigmatise them, discriminate against them." **MMHP 2:** "they are still getting stigmatized/ discriminated… the general public do not know their illness. Not educated and of course they are influenced by news, movies because they tend to perceive mental illness, people with ID as something which is very dangerous and disgusting. These are the misinformation that they get from the news and movies that sort of influence their concept and attitudes… **MMHP 3:** "…in general, they are excluded and they're usually marginalized even like people with mental health are usually.. There's usually somewhat of a stigma, they're usually marginalized to some degree but then people with ID, with or without mental health issue."

			MMHP 8: "…I suppose the issue is that people react when they see something. So I think, for example, usually when the public encounters a person with ID just going about, they may be helpful or they may not pay much attention. It's different when a person with ID is behaving slightly differently from the rest, maybe talking loudly or suddenly shouting kind of thing, in those cases, I suppose the public might react and that is something we sometimes see.."
Ideal characteristics of healthcare professional - Being patient - Having prior knowledge - Being observant - Willing to work in a team - Seeing the person behind the diagnosis - Facilitating community integration		1, 2, 3, 4, 6, 7, 8	**MMHP 1:** "I think a lot of patience. Because it is not easy to communicate with them, try to understand what's going on and manage the behavioural issues. You need a lot of patience and kind heart, big heart" **MMHP 2:** "I think patience is very very important because most of the time after they are trained, they can communicate but they cannot communicate very effectively using abstract words…you have to use very simple language and that simple language has sometimes need to be repeated over and over again so this is the core attitude that you need in order to deal with this group of people." **MMHP 3: "**someone who can sees the inherent dignity of them. Someone who cares about their rights as people. So I think someone who is patient. Someone who is truly an advocate, who feels strongly about working with people with ID." **MMHP 4:** "A lot of patience, acceptance... perseverance, yeah erm it's very easy to give up on, especially

			when things are not going through…" **MMHP 7:** "ability to have empathy, not only towards the child, but also towards the parents. Because a lot of times, parents and caregivers of these children are already struggling in terms of either their diagnosis."
Service recommendations	**1. Having more resources and time** - Training in conducting behaviour assessment and intervention - Training in nonpharmacological interventions - Acquiring skills to communicate and work with other professionals - Knowledge of resources in the community that can help people with ID - Opportunities for more experience working with this client population	1, 2, 3, 6, 7, 8	**MMHP 2:** "During the masters course. Especially those young doctors who are interested. Or maybe for specialists who wants to specialise in this field." **MMHP 3:** "going in and you just got to start interacting with people and their families. You'll learn what it's like once you get in to accumulate experience. So opportunities for that would be crucial…" **MMHP 3:** "is we did a lot of visits to special school….in mind that there are all these other resources out there. You should kind of understand what they're about and what they provide, therefore I could visit the sites and view the services that they provide. The services that they provide is important as well." **MMHP 8:** "we have managed to train people more in the area of ID. For example, in my hospital, we have a specialized department set up many many years ago. Also, being able to have that in the curriculum for training undergraduate and postgraduate students, and in the medical and other healthcare disciplines. These have been quite helpful."
	2. Training community	2, 3, 4, 5, 7	**MMHP 2:** "…Ultimate goal is still the

	support staff - Training in identifying and managing challenging behaviours **-** Changing negative perceptions and misattributions e.g regarding sexuality issues - Improving consistency of care - Ensuring smooth transition for people with ID to a new environment		same, to re-adapt them back into the community …It will be great if we can conduct home visits like what they did in the psychiatry ward. Right now we still don't have that. Home visit by a community team that consists of the doctor, psychologist and the speech therapist , we form a group, visit them say four or five houses a day, interview the patient and their family members, look at their home structure, environment." **MMHP 4:** "in terms of training, again it's the resources for staff, language spoken in terms of communication and it can be a foreign environment because it's different....let's just say the person is from home and is transferred to ID...the difficult can be there in terms of transitioning because they are so used to back home. I don't know...there can be a tendency to generalise...so much so it's structured, then my impression would be everyone is just operating the same." **MMHP 5:** "the nursing home environment, it's not that they are neglected but they are treated the same. There will always be food...so it's not so much of neglected but the challenge is somewhat different is that they tend to feel not as cared for"
	3. Empowering family carers **-** Helping family carers to gain confidence in managing challenging behaviours at home - Helping family carers to accept the diagnosis - Engaging with family	2, 3, 4, 5, 6, 7, 8	**MMHP 2: "**we need to engage with the family members more…they need to have a proper education on how to look after this group of people and as well as how to handle them. And also education for the patients of course if they understand." **MMHP 3: "**the expertise, the psycho education, the expert in the field could

	members during hospitalisation - Family carers find gaining knowledge and skills useful - Addressing carers' stress and burnout		provide probably may benefit the family caregivers." **MMHP 3: "**caregiver burden is a lot, stress on their part, so unable to manage. They don't want to deal with it alone. Again, because of the amount of burden they have, they'll probably welcomed all types of services."

Appendix 6: Example of a worked interview transcript (SMHP) (Links to Chapter 5)

Emergent Themes	Original Transcript	Exploratory Comments
	I: Thank you for joining the study. So can you share with me what is your experience like working with someone who has ID and mental health problem? What is the experience of providing the care to this group of population?	
People with ID are admitted due to behavioural issues (1) People with ID unable to express their needs (2) Having more vulnerabilities to develop chronic medical conditions (3)	A: So i think the people with ID, this group of people are very unique. Patients who are admitted into acute ID ward, the criteria is they need to have behavioural concern, last time we call this the challenging behaviour. So we find this group of people different from people with mental illness. For example, they have a lot of sensory issues, very sensitive to noise and sometimes even to the light. And also communication issues, they have difficulty to express their needs to the staff. Our staff are also unable to understand them. The patients also has physical disabilities and medical issues such as diabetes and arthritis compared to the people with no disabilities.	Admission to the hospital -> People with ID having behavioural issues ➔ Can be due to various factors Difficulty for people with ID to express themselves -> communication difficulties ➔ Unable to understand them, difficulty to find out about medical history Also have various medical issues – vulnerability to developing chronic conditions
	I: Can you share with me your experiences in the typical work day and in the ward setting?	
Role as a healthcare professional (4)	A: Because i am in the supervisor role, usually for me i try to supervise my nursing team to provide the nursing care to the patients. Like bathing, serving medication, meals and also conducting group activities for the patients.	Explaining his role working with people with ID ➔ Training and supervision to other nurses
	I: What has been challenging when working with this group of people?	
Too crowded to stay in	A: The challenges maybe starts first from the environment because now it is 36	

the hospital (5) People with ID lacked to make choices in hospital (6) Denied opportunities for social interaction (7) Staff lacked knowledge to take care of them (8) Family carers abandoned them in the hospital (9) Family carers not keen for their family members to be discharged from hospital (10)	bedded. Either they stay in the day lounge or in the dormitory. I think this is too crowded for them. The routine is fixed for them. For example, in the morning, we will wake them up for medication and for breakfast. Timing for stretching activity are also fixed so they don't have much choice of it. Definitely we are thinking about the patients themselves. Different patients have different behavioural concerns. Sometimes they really can't mix with each other and bad influence with each other. So talking about staff, some of the staff are mental health trained but they are not trained for taking care of people with ID. They really don't understand the needs of patients with ID. Sometimes they would use restrictive practice such as restrains or injections to take care of this group of patients. The other challenges is the patient's relative. Before the relative comes, we need to sign a contract with them to encourage them to actively participate our therapeutic program and they need to agree on our discharge plan. However once the patient is admitted here, sometimes they will disappear and not attending family sessions, leading to reject the patient. They just dump the patient here. Which is also an issue. They don't want to be in involved. They just think like ok since i handover the patient to you so ok now it is not my problem. Now another issue is sometimes they feel since my family member / loved one is so well taken care by the whole team then i don't want to discharge the patient to anywhere else. To home or to a shelter home or long stay. So they will come up with a lot of reasons/ excuses during the discharge phase, like they can't get a maid or a proper nursing home so they are unable to take care of the patient or support. Actually we face a lot of challenges.	Overcrowded occupancy – difficult to manage Having fixed routine -> less opportunities for them to express their wishes and choices ➔ Regimental ➔ Difficulty socialising with other people with ID Staff may not be trained to take care of people with ID ➔ Use of restrictive practices Family carers -> may not want their loved ones to be discharged from the hospital ➔ Thinks that it should be the responsibility of healthcare professionals to continue taking care of their loved ones ➔ Cut off contact from their loved ones with ID Family carers -> not keen for them to be discharged to community shelter homes ➔ Seek ways to delay discharge for their loved ones ➔ Results in people with ID having to stay longer than necessary
People with ID having aggressive behaviours (11)	I: Just now when we were talking about working with patients with ID, you mentioned about the behaviours right. What are the mental health conditions do you see in the ward today? Like what are some of the behaviours? A: Behaviours like say for example, the most significant ones is the aggressiveness. Have to watch the staff and other patients. Self-hitting or injury behaviour. Another one is like some water drinking or food grabbing.	Examples of behavioural issues -> self-injury, aggression
Mental health problems in people	I: Then in terms of mental health problems? What do they usually present? A: Sometimes we know that they have depression or schizophrenia as well.	Comorbid mental health issues – Depression and schizophrenia

with ID (12) Difficulty to identify mental health problems (13) Use of medication to treat mental health symptoms (14) Having passion for this job (15) Allowing people with ID to have choices and control (16) Healthcare professionals tend to make decisions on their behalf (17) Perceives that people with ID are not capable to make choices (18)	I: How are these mental health symptoms being manifested in the wards? A: Sometimes actually we don't know that they are suffering their mental illness or their behavioural concern. So it's like say do we need our staff to have observation. Like ask for the doctor for opinion and whole team effort to think if this is really part of mental illness or just behavioural concern. If i say, we think this is mental illness right, that means it's more on the medication. We need to adjust on the medication. I: For yourself like how do you find yourself working with this group of people? What let you work with people with ID? A: Definitely is the passion. I'm thinking that... so this patient i still believe that this person self help care approach right, i think the most important thing for this group of people is the choice and the control. Actually we should not walk for them but we should walk with them. Because I feel that a lot of times we are making decisions for them and by right, we should discuss with them about the plan and the treatment care with them. For example like which nursing home? Do you want to go nursing home or you want to go home or you want to go what kind of ward or kind of activity you want to participate? So let them know actually they have a choice. They can choose but not just plan nicely for them and they just need to follow. I: So in terms of making choices, do you think they can make choices about their health and where they want to stay? A: Unfortunately now can't because we have limited choice for them. Sometimes our belief is like thinking that maybe they because of their intellectual level, they may not know what the best is for them. So sometimes we are going to make decision with them. Usually the team most likely they will just share the decision	Difficulty to identify mental health issues ➔ Often masked by the behavioural challenges ➔ Tries to observe the person for long period ➔ Medication is often used to manage mental illness Working with this population -> needs to have passion Facilitating opportunities for them to have choice and control regarding their life Healthcare professionals -> override their decisions or do not take them into consideration ➔ Often the decisions are made for them and the people with ID have to follow People with ID are unable to make choices when staying in the hospital - Perceive that they do not know how to make 'good' choices

People with ID are not aware of their treatment plans (19)	with the family member rather than the patient themselves. I: So sometimes when the family members and the patient has differing views regarding treatments or where they want to be discharged. How would you manage or your team managed that?	People with ID are not informed of the treatment options and decisions - Mainly shared with family carers
Healthcare professionals discussed with family members (20)	A: Team manage usually, like what i said, discussed with family members. Definitely. I: Are there any limits to what they can make and what they cannot make in terms of their choices?	Family members are often approached to make decisions for their family member with ID
Customising the activities and schedule in the ward according to their interests (21) Trying to find out about their interests (22)	A: In the ward actually we try. Now we included the PTA (Patient therapy assistant) to help us to conduct the patient's individual activity for them. In the past, actually we have the weekly group activity for our patient. Schedule. For example, Monday is art and craft, Tuesday is board game, Wednesday karaoke, Thursday movie session. This schedule is already fixed. That means on that day, patient like board game, don't like art and craft. We will say sorry today is Monday you need to wait for Tuesday for board games but now we think that we want to focus on the individual. So we ask the PTA to find out patients' like and dislike. We come up with the individual plan for them. I think this is a huge improvement but however timing is still with me to fix the timing. For example, a patient want to play more in the morning, 9am. I say sorry you need to wait until 10am then we will start the game. I: Then at the ward, what do the nurses do when they notice any behavioural concern? Or challenging behaviours?	Trying to empower people with ID to have choices in the activities that they like to do Knowing the interests and likes of the person with ID ➔ Develop a schedule with their likes and interests in mind
Developing behavioural support plan to address the behaviours (23)	A: For challenging behaviours, for support plan, so we come up with the proactive strategy and reactive strategy for each patient. An example, now a patient become aggressive, in terms of violence, he is going to fight with staff or hit other patients	Developing behavioural support plan to address the behaviours when they manifest in the wards

Use of restraints for short term (24) Finding out the root cause of behaviour using functional analysis (25)	then definitely we have no choice, means sometimes we need to put out the fire, then we may need to put out the crisis fast, otherwise we need to restrain him, calm him down or give some injection. However, for long term, we have the proactive strategy. We find out what is the root cause. We call it the function of the behaviour. What is the cause of aggressive behaviour? Is it he want to get something? Get attention? Or he want to communicate with any of the staff? So we find out this. Then we come up with a treatment plan accordingly. Proactive strategy. I: Then working with these people, what has been easy for you?	Use of restrictive practices as a last resort e.g harm to others or self Trying to find out ways to reduce the aggressive behaviours - Finding out the function of the behaviour - Finding ways to address their needs to reduce the onset of aggressive behaviours
Not easy to take care due to communication issues (26) Healthcare professionals building rapport with them (27)	A: This group of the people, actually I think it is not very easy compared to people with mental illness. Most importantly is the communication. At least half of this group of patients, they have a communication issue. We don't know what actually they want. They cannot tell us what they and what's going on. So that's why we need to build up the rapport and spend a lot of time. Maybe use like the ABC signs to try to find out their communication pattern. I: For someone who is new, for someone who wants to work with this group of people, what makes someone suitable to work with people with ID? What sort of characteristics or quality attributes do you think they need?	Healthcare professionals do not find it easy to communicate with people with ID - Struggles to know what they want - Need to explore other ways to understand what they want - E.g taking time to build rapport
Having training for new staff (28)	A: Training. I think. Because adding new staff to work so we have to provide the training. So the team, we have 3 day course, intensive training for the new staff regarding management of intellectual disability. All the staff we send them to this training course, let them have some basic understanding and the basic skills to manage patients with ID. I: In terms of any qualities? You think what sort of characteristics must they have? Because you mentioned someone with passion…	Important to have training - Understanding of ID - Knowing the skills to manage the behaviours

Infantilising them as 'children' (29) Spending time to build rapport with them (30)	A: Yeah definitely the passion is very important. You really need to, like what i said show a lot of the patience. Sometimes they can feel that this group of people are actually... I talk to them is like naughty kids. Especially the kids with the really aggressive behavioural concerns, Challenging behaviours. Very difficult to manage them. Sometimes you really need to spend a lot of time to build up the rapport with them and also to understand their communication needs. I: Why would people need to know before they consider working with these group of people? People with ID	Having patience when working with them Infantilising them as 'children' with behavioural issues - Use of the word 'naughty' – attribute behaviour issues to their personality or characteristics instead of situation? Need time to build rapport to understand their needs
Healthcare professionals are not given a say to work with this population (31)	A: Actually for the nursing management, they just assign to any of the ward, depends on say, the requirement of the manpower. So they don't have the choice. Say ok I want to work in the ID ward then you can come. Because we always tell staff that you are required by the hospital, not by the individual. So it's not like I say you don't have any choice. It all depends on the requirement of the wards. *(Transcript continues on)*	Healthcare professionals don't have a choice working in specialised services

Appendix 6 (Continued) – Example of a worked interview transcript (SMHP) (Links to Chapter 5)

Theme No 1: How people with ID are referred in the hospital

Sub Theme no 1: Difficulties that family carers experienced

- Family carers abandoned them in the hospital (9)
- Family carers not keen for their family members to be discharged from hospital (10)
- People with ID having aggressive behaviours (11)
- People with ID are admitted due to behavioural issues (1)
- Family carers becoming too stressed and overwhelmed to take care of their family member post discharge (48)
- Lack of support in the community to help family carers (49)

Sub Theme no 2: Health issues that people with ID experiences

- People with ID unable to express their needs (2)
- Having more vulnerability to develop chronic medical conditions (3)
- Mental health problems in people with ID (12)
- Difficulty to identify mental health problems (13)
- Use of medication to treat mental health symptoms (14)
- Side-effects of medication may affect adherence (52)

Theme no 2: How people with ID are managed in the hospital

Sub theme no 1: Lack autonomy to make decisions regarding their care

- People with ID lacked to make choices in hospital (6)
- Denied opportunities for social interaction (7)
- Healthcare professionals' preference for people with ID to be discharged home (38)
- People with ID lacks autonomy in their discharge (39)
- People with ID having more freedom when they are discharged home (40)
- Being a burden to society due to poor prognosis (34)
- Viewing them as "hopeless" (35)
- People with ID are not aware of their treatment plans (19)
- Too crowded to stay in the hospital (5)

Sub Theme no 2: Alternative nonpharmacological strategies to manage challenging behaviours

- Developing behavioural support plan to address the behaviours (23)
- Finding out the root cause of behaviour using functional analysis (25)
- Use of behavioural support plan to manage their behaviours (50)
- Use of positive reinforcement to encourage medication adherence (51)
- Customising the activities and schedule in the ward according to their interests (21)
- Trying to find out about their interests (22)

Sub Theme no 3: Getting family involved during the person's admission

- Positive experiences of family carers being involved in learning from healthcare professionals (46)
- People with ID are more likely to be discharged home when family carers have closer relationship (47)
- Involvement of family carers during the early period of admission (53)
- Family carers find it useful to know the root causes of behaviours (56)
- Teaching family carers the strategies to manage the behaviours (57)
- Positive experience – helping the person with ID to communicate with alternate methods (58)
- Positive experiences where people with ID are not readmitted (59)
- Family members understand their loved ones the best (42)
- Family members become more confident after learning strategies (43)

Theme no 3: Healthcare professionals' role in providing services to people with ID

Sub theme no 1: Negative attributions of healthcare professionals

- Use of restraints for short term (24)
- Staff lacked knowledge to take care of them (8)
- Healthcare professionals tend to make decisions on their behalf (17)
- Perceives that people with ID are not capable to make choices (18)
- Healthcare professionals discussed with family members (20)
- Infantilising them as 'children' (29)
- Healthcare professionals are not given a say to work with this population (31)
- Healthcare professionals are told of the risks for taking care of this population (32)
- Lack of knowledge leads attributing behaviours to their personality (33)
- Starts to pity them and viewing them as 'children' (36)
- Will avoid working with them (37)
- Healthcare professionals obtain information from family members (45)
- Lack of adequate time to have training (60)
- Not easy to take care due to communication issues (26)

Sub theme no 2: Ideal attributes of a healthcare professional

- Role as a healthcare professional (4)
- Having passion for this job (15)
- Allowing people with ID to have choices and control (16)
- Spending time to build rapport with them (30)
- Healthcare professionals building rapport with them (27)
- Addressing family carers' concerns and expectations facilitate discharge (54)
- Encouraging people with ID to be more involved during the hospitalisation (55)
- Allowing people with ID to make decisions (64)

Sub theme no 3: Recommendations to improve attitudes and competency

- Having training for new staff (28)
- Learning is mainly self-initiated (61)

- Having case discussions (62)
- Having resources online for easier access (63)

Theme no 4: Having more resources in the community for people with ID

- Professional staffs in disability homes lack training (41)
- Support staff lack time to spend with individual people with ID (44) 0
- More community resources that cater to this population (65)
- Need to have more work opportunities for people with ID (66)
- Comparison of work opportunities between SG and other countries (67)
- Employers are not keen to hire people with ID (68)
- Having public education to raise awareness which facilities easier access to community facilities (69)
- Public prefers people with ID to be segregated from the community (70)

Appendix 7: Table of themes for all SMHPs (Links to Chapter 5)

Main Theme	Sub Themes	SMHP	Examples of quotes
Role of specialised healthcare professionals	**1. My work is challenging** - Initial feelings of fear - Negative feelings start to decrease with more experience - Comparison with general population Feeling unsure if behavioural issues are addressed adequately - Challenges in communication - Working closely with other healthcare professionals in MDT setting - Helping people with ID to access community services - Working with caregivers - It takes time to adjust to the work environment and to change your perceptions - It's a huge learning curve - Try different ways to manage mental health problems - Sessions require more preparation	1, 2, 3, 4, 7, 8	**SMHP 1:** "You will feel like they may trigger any time during a session...yeah and I guess that is also due to lack of experience and exposure, hence you end up having a kind of fear at the very beginning." **SMHP 1:** "I have to change the way I communicate with my patients and being more aware of the communications needs." **SMHP 2**: "Can be stressful because understanding of the patient. So communication can be an issue…. Especially when they have behavior issues. Eating non-edible things, playing with urine or feces, self harm, biting others, don't take care of their own hygiene, those things can be quite challenging for the nurses to look after especially for adult. **SMHP 3:** "…think most people would be scared, they would be nervous. Yeah there is a lot of, maybe there is a lot of stigma that these people would get aggressive …come and hurt you." **SMHP 7:** "I would be working with their caregivers more.

			Number one understanding the issues, challenges that caregivers face in their care. Similarly empowering and journeying with them in this journey of helping them regarding finding for suitable services, addressing caregiving or parenting issues."
	2. Building a therapeutic relationship - Taking more time to understand the person with ID - Adaptation of techniques used to treat them - Relying on nonverbal cues to identify signs of distress - Differences in opinion regarding the use of medication - Development of behavioural support plan to address the behaviours - Understanding the person behind the diagnosis - Using visual aids, simple language and provide structure - Avoid 'infantilising' them - Use of restraints (-ve) - Being penalised for spending too much time with them	1, 2, 3, 4, 5, 6, 8	**SMHP 2:** "So if they don't tell you, you have to find other signs to discover whether they face all these or not. For mood disorders, the swings can be bad but then for ID patient, it's really based on your clinical observations." **SMHP 2:** "Sometimes if they are in good mood, they can be helpful too. They will help you do things." **SMHP 3:** "whether they are willing to take the time and effort to know the other individual. And knowing that it is not just having simple conversations, so often times, verbal communication is out, so whether they will take the effort to know the other person better through nonverbal means, or just playing a simple game..."
	3. Desirable staff attributes - Having a passion for the	1, 3, 4, 5, 7, 8	**SMHP 1: "**They need to be flexible, open-minded. Flexibility is very important

	job - Being an advocate for clients - Having prior experience - Willingness to learn, skills can be developed later - Self-initiated ongoing training - Being comfortable working with different stakeholders - Being calm and aware of your own emotions/thoughts - adequate self-care - Being flexible, know what theoretical knowledge does not apply in practice - Limit your expectations of treatment outcomes		because you never know what case comes to you and if you are going to use whatever theory that is being taught in school and try to follow ABC and D, a lot of time it may not help. And also good observation skills." **SMHP 3:** "I guess most important would be the passion, so you know whether you are interested to work with them in the very first place." **SMHP 5:** "If you ask me specifically in ID, have to be patient also and teamwork is very important, because dealing with sensory, social issues and stuff like that." **SMHP 7:** "So when you're journeying beside them… Sometimes they can be a bit of resistance first, they can be a little bit of opening up, so that patience, and perceptiveness in looking at issues in different angles. I believe these traits, perceptiveness, keen insight would be crucial. Other things like resourcefulness can be trained. Sometimes we find that we have to think out of the box too if you are left with a certain amount of resources and options, what else can be done."
Ensuring continuity of care	**1. Involvement of family carers during treatment**	1, 2, 3, 4, 5, 7, 8,	**SMHP 1: "**parent will know a little bit more about the

	process - Family carers have more understanding of the person with ID - Carers start to lose hope - Carers struggle to manage the behaviours when they are discharged from hospital - Difficult to discharge - Carer may not be receptive to services, others find services useful - Important to involve family during the treatment process - Difficult to carry out the wishes of people with ID - Mainly consult and discuss with family members - Family members consent on their behalf for treatment - Denied opportunities to have meaningful lives, family carers over-protective - Being expected to 'fix' the problems	9	patients themselves and actually gives us a lot more insight of the patient's behaviours at home and communication needs at home… with parents, you can give very specific intervention or strategies because it's one-to-one at home and it's easier." **SMHP 2: "**that's the time that the family members might be really frustrated and they feel helpless, so the moment they bring the patient back, they see they behave really destructively, so they have to send the patient back to hospital…I think the faith, the belief that this patient can become better, will slowly be faded." **SMHP 4: "**we usually discuss with the family members and because most of them stayed at home, they do not have the capacity to decide the treatment, they don't even understand what type of treatment that they are receiving, so the care and implementation of the treatment is mainly lies with the family members." **SMHP 6:** "…we need to teach them what are the strategies we going to use to help the patient with ID with behavioural concerns. So that means we really want them to actively participate during

			the patient's hospitalization."
	2. Working with residential support staff - Support staff lack training Skills training and clarifying misconceptions that support staff may have - Training for support staff to improve retention - Lack of 'buy-in' from support staff - Feelings of frustration when behavioural problems remain unresolved - Ensuring that behavioural strategies are consistently carried out in the residential setting - hospital bed blocking – restrictive environment - Improving the services in the community that people with ID can access - Providing opportunities for clients to have a say	1, 2, 3, 4, 6, 7, 8	**SMHP 1 "**whereas in nursing home or ID home because there are so many residents that the nursing staff has to take care of, usually they may give you a little bit about ambiguous information about this patient… if you ask them for triggers usually, they can't really tell as much..." **SMHP 6:** "But of course, the care, to be frank, the disability home, nursing home, the staff there still lacks training. They don't have much experience in taking care of this group of patients." **SMHP 7: "**Another group would be the formal caregivers in institutions. their residents have condition or behaviours, challenging behaviours and resided on our ward for treatment for a period of behaviour therapy, you will meet the staff there for better understanding, the environment, and the social interaction of the patient or their resident and see how we can provide positive behavioural support for the resident, addressing the behaviours." **SMHP 8:** "understanding the behaviours and provide strategies. Especially when they went through therapy and that we give them some

			follow up exercise to do at home, so they will find it useful."
Disempowerment of service users	**1. "They should be given more choices"** Difficult to accede to their wishes, overruled by family members' wishes - Safety issues have to be considered when making decisions - Assumption that they lacked capacity and do not understand their condition - Assessment to determine capacity - Infantilising them who is? - Healthcare professionals tend to make decisions on clients' behalf - No opportunities to have social or romantic relationships - Helping people with ID to understand the decisions being made for them - Clients lose acquired skills when they lack opportunities to be independent - Some decisions made may be harmful for clients - Use of restraints as a way of keeping clients safe from harm	1, 2, 3, 4, 5, 6, 7	**SMHP 1: "**patients with ID who are able to communicate their needs and wants, it's very important to allow them to express their needs and wants in daily basis because then at least, whatever they want or whatever they don't want are being met and it will cause less frustration as well and I think will give them a sense of independence and control, self-control rather that having to help them all the time." **SMHP 2:** "everything is very restricted in the environment. We don't talk about the not so legal things, like sexual contact or even smoking. Don't talk about this." **SMHP 2:** "I think it is important to hear patient's voice. Like you say, this is the patient who have mild ID, who still can understand, communicate with you, autonomy and respect to patient is very important. Because he can think, he can verbalize to you what he wants, what he prefers so if that's the case, we should respect the patient's feelings, we should give enough autonomy." **SMHP 4**: "And the wishes are different for the person with

			ID which they lacked capacity, so we need to rely on the caregivers. But it will lead to another problem, if the caregiver has a different view from the healthcare professional's opinion, then it will be difficult to provide the care for the patient." **SMHP 5"**I think they have less choices which is quite poor. , I have some patients who are staying in the homes that only serve them vegetarian food and this patient likes to eat non vegetarian, so that's why she always look for parents or like when there's non-veg, she always grab for the food and generally, the mood is low..."
	2. "The public just want to get away from them" - People with ID are isolated at home due to challenging behaviours - Stigma from the public affects integration - Other barriers to accessing community services - Restricted in pursuing interests - Being a burden to society due to poor prognosis and productivity - Public continues to have misconceptions about people with ID	2, 3, 4, 5, 6, 7, 8	**SMHP 2: "**So if you ask me, healthcare provider personally, I think by putting everyone into a big cultural background in Singapore, can be hard…you want to bring patient to play sports, you want to bring patient to shopping mall, it's hard because honestly, if you ask nurse clinician, if patient abscond, whose responsibility?" **SMHP 2: "**Because once you're labelled mental illness, people look at you differently. I think ID group is a very unfortunate group." **SMHP 3:** "so sometimes like...most of them, I guess, are just kept at home and

			then, these behaviours would worsen” **SMHP 4: “**The public may perceive patients with ID as kind of dangerous, unpredictable. And also the patient with ID… so because of stigma, so generally it will cause kind of barrier for the patient with ID for them to integrate back into the society. This is from the public perspective kind of stigma, negative view.”’ **SMHP 5:** “I think sometimes they don't have the allowance to be in many activities because of their limitations, they cannot join many other activities they want in the community”
Improving clinical practice - Addressing human resources - Collaboration with community partners - Training, experiences in non-pharmacological interventions and sufficient time - Having more resources that are easily available - Organisational support for staff training		1, 2, 3, 4, 5, 6, 7, 8	**SMHP 1: “**: Yup, professional overseas… the courses that are specific to ID are very limited for speech therapist.” **SMHP 2: “**I think together, we can do more for the patient. Especially from the management, they have to give more authority, give more green light, give more space and resources to the patient and also to the ground staff. And then only they can do better. If nothing else has changed, nothing more is supported, if you keep asking the front nurses to do more, there is a limitation.”

- Peer support to address high staff turnover - Informal consultations with colleagues - Having overseas experts or funding for overseas training/work experience - Opportunities for specialised training - Addressing negative attitudes from staff starting work without experience - Helping clients to have social relationships			**SMHP 3: "…**building up on my knowledge. Probably having to go through postgrad, understanding a bit more about the mental health aspects because all these while, I only worked with people with special needs, so when I come to the hospital and see comorbidities, sometimes I struggle to deal with it." **SMHP 8:** "my supervisors are able to give me support and training but i would like to do more collaboration with different organisations especially community, to see how we can include our clients into the society rather than staying at home or in the hospital."

Appendix 8: Participant Invitation Letter (Links to Chapter 4 to 8)

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

I would like to invite you to participate in a research study entitled "**Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore**". The study is being conducted at IMH and will contribute to the research project for a PhD (Psychology) at the University of Birmingham by Jonathan Ee.

The purpose of this study is to explore the attitudes of healthcare professionals towards adults with neurodevelopmental disorders and mental illness in Singapore. We hope to learn about the experiences of healthcare professionals working with this population and family carers as they navigate the mental health services with their family members. Once you have given your consent to participate in this study, you will be engaged in an interview by a researcher of this study. The interview will last for up to 60 minutes.

By participating in this research, you will contribute towards enabling the healthcare professionals to identify service delivery and training gaps when working with this group of people and may lead to organisational and policy improvements in Singapore.

If you have any questions about your right as a research participant, please contact the NHG Domain Specific Review Board Secretariat at 6471-3266. You can also find more information about participating in clinical research, the NHG Domain Specific Review Board and its review processes at www.research.nhg.com.sg.

If you have any questions about this study, please feel free to contact the Principal Investigator of this study, Ms Lim Jan Mei, at Tel: , or Co-Investigator, Mr Jonathan Ee at Tel:

Thank you.

Lim Jan Mei (Ms)
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Appendix 9: Participant Information Sheet and Informed Consent Form (Caregivers) (Links to Chapter 6)

1. Study Information

Protocol Title:

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

Principal Investigator & Contact Details:

Ms Lim Jan Mei

Clinical Psychologist

Adult Neurodevelopmental Service
Institute of Mental Health
Buangkok Green Medical Park
10 Buangkok View
Singapore 539747

Co-Investigator:

Mr Jonathan Ee

Doctoral Researcher
University of Birmingham
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B15 2TT
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+

Study Sponsor:

University of Birmingham

2. Purpose of the Research Study

You are invited to participate in a research study. It is important to us that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign this informed consent form. You will be given a copy of this consent form to take home with you.

This study is carried out to explore the attitudes of healthcare professionals towards adults with neurodevelopmental disorders and mental illness in Singapore. We hope to learn about the experiences of healthcare professionals working with this population and family carers as they navigate the mental health services with their family members.

You are invited because you are:

(1) a family caregiver of a service user who is engaging mental health services in the hospital

This study will recruit around a range of 8 - 12 family caregivers from Institute of Mental Health over a period of 9 months.

3. What procedures will be followed in this study

If you take part in this study, you will be asked to attend an interview session with the interviewer (Co-Investigator). Your participation in the study will last up to 60 minutes. The interview will be audio taped and destroyed after the research study.

If you agree to take part in this study, the following will happen to you:

Schedule of visits and procedures

Visit 1: Interview session with the interviewer consisting of up to 60 minutes at a private room in IMH. The interview will be audio-recorded which will be transcribed for the purpose of analysis. The audio recordings will be destroyed after the study has ended.

A written summary of the findings of the questionnaire is available upon request after the study has ended via soft copy. You may wish to leave your email address with the interviewer if you are interested to receive a copy.

4. Your Responsibilities in This Study

If you agree to participate in this study, you should follow the advice given to you by the study team. You should:

- Be prepared to visit the hospital for at least one session and undergo all the procedures that are outlined above.
- Keep your study appointments. If it is necessary to miss an appointment, please contact the study staff to reschedule as soon as you know you will miss the appointment.
- Inform the Principal Investigator as soon as possible about any possible emotional distress that you may have experienced.

5. Possible Risks and Side Effects

In any unlikely event that you experience emotional distress as a result of sharing about your experiences, you should:

- May wish to withdraw during the interview.
- Inform the Principal Investigator who will either refer you to emotional and counseling support provided by IMH.
- If you do not want to be referred to the primary healthcare professional, you will be given information and contact numbers of external psychological community services.

6. Possible Benefits from Participating in the Study

There is no known benefit from participation in this study. Talking about your experiences may be a cathartic process where you may have a deeper understanding of own experiences of taking care of your loved ones better. In addition, your participation may contribute to the understanding of healthcare professionals' attitudes towards individuals with

neurodevelopmental disorders and mental illness. These research findings may lead to organisational and policy improvements for the hospital's management and Singapore regarding services for individuals with neurodevelopmental disorders.

7. Alternatives to Participation

If you choose not to take part in this study, your family member will continue to receive standard care for their condition. In out institution, this would be regular follow-up consultations with healthcare professionals.

8. Costs & Payments if Participating in the Study

You will be reimbursed for your time, inconvenience and transportation costs as follows:

- If you attend the interview, you will be paid $20 cash voucher

9. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your loved ones' medical care or any benefits to which he/she is entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator. Confidentiality may need to be breached in order to communicate any safety concerns to appropriate services to protect the safety and wellbeing of you, your family member or other people.

You will be required to inform the Principal Investigator if you wish to withdraw from the study after the interview. The data will not be used and will be discarded.

Your doctor, the Investigator and/or the Sponsor of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you *(or your legally acceptable representative, if relevant*) will be informed in a timely manner by the Principal Investigator or his/her representative.

10. Compensation for Injury

If you follow the directions of the doctors in charge of this study and you are physically injured due to the trial substance or procedure given under the plan for this study, the National Clinical Trial Policy will pay the medical expenses for the treatment of that injury.

Payment for management of the normally expected consequences of your treatment will not be provided by IMH.

IMH without legal commitment will compensate you for the injuries arising from your participation in the study without you having to prove IMH is at fault. There are however conditions and limitations to the extent of compensation provided. You may wish to discuss this with your Principal Investigator

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

11. Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, the Sponsoring company, Regulatory Agencies and NHG Domain Specific Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you (*or your legally acceptable representative, if relevant*) are authorizing (i) collection, access to, use and storage of your "Personal Data", and (ii) disclosure to authorised service providers and relevant third parties.

"Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. This includes medical conditions, medication, investigations and treatment history.

Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected will be anonymized and entered into the Case Report Forms. These anonymized data are the property of University of Birmingham and Institute of Mental Health. In the event of any publication regarding this study, your identity will remain confidential.

12. Whom To Contact if You Have Questions

If you have questions about this research study, you may contact the Principal Investigator, Ms Lim Jan Mei *(* [redacted] *) or* the Co-Investigator, Mr Jonathan Ee, at [redacted]

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266. You can also find more information about participating in clinical research, the NHG Domain Specific Review Board and its review processes at www.research.nhg.com.sg.

If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

CONSENT FORM

Protocol Title:

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

Principal Investigator & Contact Details:

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I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction. I have also been informed and understood the alternative treatments or procedures available and their possible benefits and risks.

_____ _____

Name of Participant Signature Date

Translator Information

The study has been explained to the participant / legally acceptable representative in

_____ by _____

<insert language > *<insert name of translator >*

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of his / her participation in the study.

_____		_____
Name of Investigator / Person administering consent	Signature	Date

Appendix 10: Participant Demographic Sheet (Family Carers) (Links to Chapter 6)

Attitudes of healthcare professionals towards individuals with neurodevelopmental disorders and mental illness in Singapore

Demographic form

Participant No *(please do not fill in):* _____

Age: _____

Marital Status: Married / Divorced / Widowed / Other*: _____

Ethnicity: Chinese / Malay / Indian / Other*: _____

Highest Education Level: Degree / Diploma / A-Levels / O-Levels / No formal qualification

No of members in the family: _____

Information of family member with disability

Age: _____

Carer's relationship to family member with a disability: _____

Level of disability: Mild / Moderate / Severe

Type of services received: _____

Any mental health issues or challenging behaviours: _____

Did you receive any support to help you take care of your family member? Yes / No*
If Yes, please state any support received: _____
If No, please state reason: _____

Any other contact with people with disabilities: _____

**please delete accordingly*

Thank You

Appendix 11: Interview Schedule for Family Carers (Links to Chapter 6)

Thank you for agreeing to be interviewed for this study. Your contributions will be very valuable. I am interested in understanding your experiences of taking care of your family member with intellectual disabilities and mental health issues. This interview will last up to an hour and I may ask you to stop to ask some questions to clarify or move on to another topic.

1. Can you tell me about your family member?
    a. *Prompt: - What kind of issues/challenges does he/she faces?*
        - What do you know/understand about your child's condition?
        - How/When did you come to find out about them?
        - How did the issues affect him/her?

2. Can share how did your family member came to receive services at X*?
    a. *Prompt: - What led you to seek services for your family member? (elaborate a little about services received in healthcare and social sectors)*
        - Have anyone/professional explain the individual's condition to you?

3. What is like taking care of your family member?
    a. *Prompt: - What is your typical day like?*
        - What is easy/difficult for you?
        - What/Who help you to take care of your family member?

4. How do people respond to your family member?
    a. *Prompt: - What is their reaction?*
        - Why do you think they react this way?
        - How do you feel? How do you respond to other people's reactions?

5. How do the professional staff respond to your family member?
    a. *Prompt: - How do they take care of him/her?*
        - How do they manage his/her issues?
        - What is their reaction towards him?
        - Is there any difference between how the staff and other people respond?

6. How do you find the services?
    a. *Prompt: - What services helped your family member or is helping them now?*
    - What could be better/improved?
    - What services would you like to have?

7. What makes someone suitable to work with people with neurodevelopmental disabilities?
    a. *Prompt: - What qualities or attributes are needed to be a good worker?*
    - What do people need to know before considering working with in this field?

8. What is it like receiving support from healthcare professionals when taking care of your family member?
    a. *Prompt: - Describe what they did or do to support you. How helpful was it?*
    - What is the experience like? Have your family member and your needs been met?
    - Would you recommend others to seek similar support and services?
    - What other services would you like to have? E.g workshops to improve relationship with your family member, training, support groups etc

9. How can healthcare professionals be helped to do a good job in supporting your family member?
    a. *Prompt: - What knowledge or training do they need? Example: time, experience, resources, support etc….*

10. What is your hope for your family member?
    a. *Prompt: - Is there anything you like your family member to achieve or do?*
    - Is there anything you wish for yourself and your family member?

11. Are there any other things you'd like to say?

Thank you for your time etc. Ask if they'd like to be sent a summary of the results.

X* - hospital/non-profit organisations

Appendix 12: Example of a worked interview transcript (FC) (Links to Chapter 6)

Emergent Themes	Original Transcript	Exploratory Comments
	J: How did your son receive the service at YYY?	
Duration of services received in specialised mental health hospital (1)	C: He has been there for the past 2 yrs. Previously he was at XXX (mainstream hospital). Started to follow up from Dec 2017 in YYY, has been almost 1.5 – 2 years	Transferred from mainstream psychiatric services at the hospital to specialised mental health services for people with ID
	J: What happened to him during the 1st time?	
Dissatisfaction in services received at mainstream services (2) Side-effects of medication (3)	C: YYY gave him medicines. Due to medicines…was previously in XXX. He started taking medicines in 2015 at XXX. He gained weight as a side effect due to the medicines. Every 3mths of appointment, he will gain 5-8kg, and it is very high and he also developed diabetes. I felt it was getting worse, and there was no improvement, and he was always sleeping all the way.	Primarily treatment approach – medication - Child developed serious side effects - Carer needed to initiate in taking action to change course of treatment Carer primarily agreed with doctor's approach
	J: So do you know the name of the medication?	
Side-effects of medication (3)	C: It's haloperidol - always give him drowsy and make him sleep. Especially for children they give that. It's a liquid form. Have to give him about 2ml, about	Carer's concern about side effects of medication

Receiving information about specialised mental health services (4) Carer as advocate for her child to transfer care (5) Feelings of upset towards side-effects of medication (6) Use of problem-focused coping strategies (7) Carer views medication as beneficial to address behavioural issues (8) Noted change in behaviours after medication were adjusted (9) Carer's understanding of her child's triggers (10)	half a tablespoon. That caused him drowsiness. So I felt like cannot continue and getting worse. Then, one of my colleagues who is a parent of a student in my son's school, told me "why don't you change to tablet? You go YYY." Cos she also faced this problem. So she shared with me, your son gained weight, is getting worse and getting bigger and bigger. He was from 4XL to 6XL then to 8XL. So I thought the weight gain was only due to haloperidol. I requested XXX that I wanted to move to YYY. Was asked why, I said due to the medication. Cos XXX have this medicine only; if you want other medicines, have to go YYY, where there are more medicines. That's why I changed. Then Dr asked me why you come now. He said it's not too late but your son has diabetes already. I said yes cos I didn't know he has diabetes and they didn't tell me. I said ok, I don't want to find fault cos I know my son gained weight. So I focus on what's next I have to do. I don't want to say these people, doctor didn't tell me. I don't want to blame anybody. Dr S suggested me this tablet. I try to adjust it; if I give him two and he feels drowsy, then I minus one, giving him one in the morning and one at night. I estimate by myself. That's when he became better and did more exercises. Taking swimming, making rounds, jogging for 3 rounds, he'll come back. He cannot do 5 rounds, 5 already he'll feel like a zombie cos his blood is too fast functioning and he'll feel drowsy cos he has diabetes. So slowly I have to push another one more and another one more. Also, he just gained weight recently I think due to Hari Raya season. Have to start back again J: Then what happened in 2015 that made you seek XXX doctors? C: That time he was hyperactive. There were many changes at home. The 1st change was he cannot see different people. It means that his 1st teacher was a	- Does not help her child, feeling unsure what to do Seek other resources through word-of-mouth Hospital staff expressed reservations to change management plan Does not place blame on hospital for failing to tell her about side effects - Does it mean she does not usually challenge the doctor's decision until her child's condition worsen? Carer's attempt to experiment dosage with her child Initially feeling unsure? Carer's perceived perception that the medication dosage works for her child - Noted change in behaviours and more active Carer's beliefs -> Mostly deferred to doctor's authority and expert opinion regarding use of medication Noted differences of care between doctors at mainstream and specialised mental health services Serious side effect of developing diabetes – carer feels anger? However does not wish to place blame?

Tried to engage external help but limited success (11) Child's behaviours worsen with time (12) Recommended to take medication by other professional staff (13) Teachers' failed attempts to reduce the severity of behaviours (14) Impact of carer's life as a result of her child's behaivours (15) Carer gives up her career for family (16) Carer seeking community resources (17)	Filipino guy, suddenly another teacher came in and he couldn't take it. Cos he couldn't overcome the changes. That's why I came to know he cannot take changes. That's how the picture started. No matter what, he wanted that teacher and started to throw tantrums. After that, I was at home and there were changes at home. I hired a helper. That time I really needed a helper to help me out. So things started in 2014; these changes happened. Then 2015, only in September, I took the helper. At the same time, there were changes in school. So both at home and in school, he couldn't take it. That's when the anger came. I thought it was normal. Then the anger became violent. He started to throw things and hit me, it was quite painful and I cannot take it. We tried to figure out. Then I went to his school; at that time he was at E school. He was only 17. We discussed with the principal and teachers and I was told my son had to take medication already. As this type of case he was very violent; even in school, he would break the window. Cos he didn't know what to do and he couldn't take the changes. The teachers were always put in the room. There is, a type of room for autism children, where can bang and everything and the sound won't get so loud. So we discussed. That's when I started to bring him to XXX in 2015 and I also resigned from my job. I sent back my helper as my son couldn't take changes. My helper was only with me for 4 mths; then I sent her back cos he hit my helper. I thought this was not good. She would cover for him and say she's ok. But as a human being I had no heart to let this happen; if anything happened, I had to bear for the cost. So I told my agency I would send her back and lost my $3000 deposit. I resigned from work; I worked for 9 years. My supervisor told me it was only 1 yr short of long service. I told her no point cos between family and work, I would choose family cos I was earning for my family. All the while as a single parent, I just worked and helped out. Now my son has this problem and my mum is also weak already. She's a diabetes patient and she was also going for an operation. So I thought this was my time to quit. Before I quit, I went to MSF and asked them for help. They submitted the documents. After I resigned,	- Engages more in problem-focused coping Triggers for her child's behavioural issues Viewed her child's behaviours as violent Needing a helper – Carer feeling overwhelmed? - Having to struggle between different demands? Lacked knowledge about her child's behaviours initially, hence did not seek help early Lack support from school teachers Carer – feelings of helpless? Tried to seek professional help from school to address the behavioural issues Teachers used 'time-outs' -> lacked understanding to develop strategies to reduce the triggers of the behaviours Make changes in her environment to reduce triggers for her son's behaviours Shared her feelings of dilemma regarding letting go of helper - Needs additional help but could not keep the helper as her child is not used to a new person in the environment Carer placed/prioritise her child's needs above her - Loss of her own life after her child is born? - Gives in to her child's demands to reduce the intensity of

	they supported me till now; they have been supporting me for the past 4 yrs. J: So you received some allowance from MSF?	behaviours? Carer – resourceful, seek community resources on her own
Solely focused on her child's care independently (18) Views herself being a burden when she depends on others (19)	C: Yes they give every month. Every month they will count how much I have to pay. Usually when I'm working, I pay my PUB, Town Council. Now everything they cover for me. So it's easy for me, cos my parents are old already. I cannot depend on my siblings as they have their own families. Though they don't have kids, they have their own commitments such as paying house loans. So I also don't want to be a burden. But they support me by giving me groceries and food every month. Cos they know if they give me money, I would surely not want and not take; so they will give food. You know children with special needs; they like junk food. They like to take nuggets, hot dogs, such junk food. So that's why they cover for them by buying these. J: For him, can he converse?	Recounted examples of how the community services have helped her Beliefs – reliance on herself, does not wish to impose care burden on her siblings Views herself 'alone' to raise her child on her own Supportive relationship with her siblings - Helped carer on her own terms -> decline money Carer – does not want to be viewed as 'weak'? Siblings understand carer's struggles and tries to help
Severity of her child's developmental milestones (20)	C: Normally only a few words; like eat. Burger he'll say bur. Few words. E.g., eat eat; these types. School he'll say school. J: He has been attending E school from young?	
Lack of intervention services in	C: He was first diagnosed with autism when he was 4 years old. They put him	Child is unable to fit into mainstream curriculum - Stigma? Staff lacks knowledge on inclusive practices to

mainstream services to address the needs of people with ID (21) Differences between the availability of intervention services before and after (22) Requires overseas expertise due to limited local knowledge of neurodevelopmental disorders (23) Child requires moderate assistance (24) Difficulty for child to take care of himself independently (25) Values role as a mother and carer to provide support in spite of emotional challenges (26)	in PAP (mainstream kindergarten) but there was a problem at nursery. So from there, I withdrew him from PAP. J: Oh then where did he go after PAP? C: I was pregnant then, after PAP, I had to see doctor. He was just at home for 2 yrs. He went to school when he was 7. In 2005, he went to Rainbow Centre (school for special needs). Quite fast it's been. Then all the while he has been receiving therapy at KKH. At that time, there were not many doctors in Singapore that specialised in this condition. Now there are many but last time not yet. J: Does he have mild ID? C: Yes I think the doctor came from Australia to diagnose him. Then they discussed with Singapore doctors, too and I was told this was a special case that we come to know as autism. He's not high functioning. He's not 100, low; he can't bathe himself. My son is 100, so it's only the 20-30s. About 1 month to 1 year baby; when he was 5 years old when they diagnosed him. So that's quite a very small baby. Now he's 22 but his IQ level is like 10-11 years old level only. Even bathing I still have to help. Peeing and everything we have to wash. He can't reach out; he'll ask for help and we'll be waiting there at the toilet. Once he was in the toilet for an hr. I went to the market and came home. I thought he was sleeping but he was in the toilet for one hr and sweating all the way. Then I have to bathe him. It's not an easy task; there's	address her child's special needs Attend special needs school Acknowledged the difference in competency in the past as compared to current - Possible share that she feels more 'lost' and stressed in the past? Due to personal family commitments? Hired professional healthcare staffs from overseas - Share their expertise with local healthcare professionals Shared her struggles taking care of her child - Not independent in taking care of himself Feelings of guilt? For not anticipating her child's needs "enjoy the pain" – indicate her strong role as a mother to provide unconditional love towards her child regardless of how difficult it was for her

	pain but I just enjoy the pain as well. In the end I'll be happy providing a service for him. *(Transcript continues on)*	Feeling happy – taking care of her child fulfilled her role as a mother?

Appendix 12 (Continued) – Example of worked interview transcript (FC) (Links to Chapter 6)

THEME 1: Use of biomedical approach to address challenging behaviours

- Feelings of upset towards side-effects of medication (6)
- Side-effects of medication (3)
- Carer views medication as beneficial to address behavioural issues (8)
- Noted change in behaviours after medication were adjusted (9)
- Carer's understanding of her child's triggers (10)
- Child's behaviours worsen with time (12)
- Recommended to take medication by other professional staff (13)
- Teachers' failed attempts to reduce the severity of behaviours (14)
- Severity of her child's developmental milestones (20)
- Differences between the availability of intervention services before and after (22)
- Child requires moderate assistance (24)
- Perceives her child's behaviours as "violent" (29)
- Carer sought help when she could not manage her child's behaviours (30)
- Carer's lack of awareness of the side effects of medication (34)
- Describing her child's daily routines (35)
- intervention services are focused on improving adaptive skills (36)
- Lack social interaction with other people (37)
- Carer's attempts to address her child's health issues (38)
- Carer's strategies to calm her child (39)
- List of activities that child participates in school (40)
- Lack of knowledge regarding nonpharmacological approaches to manage behaviour (54)
- Learns to administer appropriate medication dosage after trial and error (65)
- Views medication as the only solution to manage her child's behaviours (66)
- Child did not display any negative behavioural reactions when going to YYY (57)
- Limited community engagement for her child (83)
- Carer's believes that the behaviours are due to organic issue (80)
- Carer becoming confident of managing her child using medication (78)

Theme 2: Prioritise her child's needs before hers

- View her child's diagnosis and caring for her as a "gift" from God (94)
- Carer's relationship with her child (55)
- Carer as advocate for her child to transfer care (5)
- Use of problem-focused coping strategies (7)
- Impact of carer's life as a result of her child's behaviours (15)
- Carer gives up her career for family (16)
- Solely focused on her child's care independently (18)
- Views herself being a burden when she depends on others (19)
- Difficulty for child to take care of himself independently (25)
- Support from family to take care of her child (46)
- Values role as a mother and carer to provide support in spite of emotional challenges (26)
- Views taking care of her child as her own responsibility (41)
- Carer's strong views about her role as a mother – not to give up care to others (85)
- Carer's feelings of pride towards her child's achievements (75)

Theme 3: How her child is treated in the public

- Lack of experience from mainstream professionals to carry out health test (79)
- Disappointment in negative reaction from the public towards her son (42)
- Views herself helpless and powerless to change negative perception (43)
- Fears that her child will behave violently in public (44)
- Difficulty to leave her child unsupervised (45)
- Concerns that her family members are unable to manage his behaviours (47)
- Public lacks understanding of her child's behaviours (48)
- Learning to accept the negative reaction and questioning from public (49)
- Neighbours have grown to understand her child's behaviours (50)
- Helping to spread awareness about her child's condition (51)
- Public perceived the carer did not properly educate her child (52)
- Carer's strategies to reduce/minimalise negative reaction (53)
- Views herself helpless and powerless to change negative perception (43)

- Carer's attempts to manage her child's behaviours in public (32)
- Perceived her child to be a "lost cause" by healthcare professionals (33)
- Tried to engage external help but limited success (11)
- Carer's believes that negative reaction towards her child will continue to persist (98)
- Mainstream healthcare professionals' negative reactions towards her child (31)

Theme 4: Carer's preference to seek specialised services

- Carer seeking community resources (17)
- Duration of services received in specialised mental health hospital (1)
- Dissatisfaction in services received at mainstream services (2)
- Receiving information about specialised mental health services (4)
- Lack of intervention services in mainstream services to address the needs of people with ID (21)
- Requires overseas expertise due to limited local knowledge of neurodevelopmental disorders (23)
- Carer values healthcare professionals' collaborative consultation with her (27)
- Strong trust towards healthcare professionals (28)
- Carer's perceived satisfaction with the specialised mental health services (56)
- Reason for seeking specialised services (58)
- Long waiting time at mainstream services (59)
- Lack of empathy from mainstream doctors to address carer's concerns (60)
- Carer's feelings of frustration towards mainstream professionals (61)
- Feeling 'defeated' with professionals' pessimistic prognosis (62)
- How did her child came to receive specialised services (63)
- Views the location of specialised service quite far (64)
- Continues to follow up at mainstream healthcare services (67)
- Having patience to work with people with ID (68)
- Example of healthcare professional being patient (69
- Specialised healthcare professionals anticipated carer's needs (81)
- Importance for healthcare professionals to have prior experience (70)
- Feeling a sense of trust for specialised doctors to care for her child (71)

- Feeling surprised that the specialised doctors know how to manage her child (72)
- Importance to have professional qualifications (73)
- having passion for working with people with ID (74)
- Healthcare professionals must tend to the people with ID needs (75)
- Considerate, being selfless – attributes of healthcare professionals (76)
- having passion for working with people with ID (74)
- Having a good rapport with people with ID when working with them (76)
- Carer feeling sense of support from specialised doctors (77)

Theme no 5: Carer's worries about her child in the future

- Carer's dilemma to consider professional staff to care for her child (82)
- Carer's preference for professional staff to take care of her child when she is not around anymore (84)
- Carer views of not wanting to burden others (86)
- Carer's beliefs that she is the only suitable person to take care of her child (87)
- Carer worries that her child may become a burden to other family members (88)
- Making plans to ensure continuity of care (89)
- Carer feelings of happiness when her child is happy following her sibling's visit (90)
- Views self as a primary carer and making personal sacrifices (91)
- Carer's hopes for her child (92)
- Carer does not identify with other carers who hopes their child will be normal (93)
- Expressed wish that her child will be happy and take care of himself (95)
- Worries about her child not adjusting well after she is no longer around (96)
- Carer's prepares her younger son of becoming the carer when she is no longer around (99)
- Carer express hopes that her son will not become a burden (100)

Appendix 13: Table of themes for all FCs (Links to Chapter 6)

Main Theme	Sub Themes	FCs	Quotes
Making sense of behaviour	**1. Not easy to take care of someone with behavioural problems** - Change in lifestyle - Feeling confused regarding the behaviours - Feelings of frustration regarding taking care of family member - Taking care of family member takes up a lot of resources - Difficulty accepting changes in behaviour - Permissive towards family member's demands - Coping with managing the behaviours – e.g. using humour - Relying on domestic helper - Struggling to manage other demands in life	1, 2, 3, 7, 8, 9	**FC 2:** "Now, she is changed and avoid all the people there. I don't know what happened. Actually if you want to take care of her simply, just take care of she wants and follow her wishes." **FC 3:** "Sometimes, want to hit parents or other people. Has been longstanding issue…he likes to fight. This behaviour has yet to change. So it is very stressful, troublesome for us." **FC 4:** "At the same time, there were changes in school. So both at home and in school, he couldn't take it. That's when the anger came. I thought it was normal. Then the anger became violent. He started to throw things and hit me, it was quite painful and I cannot take it." **FC 6:** "Then big hooha case came that police was called in. He hit her at the centre. She said first two times he hit her…"
	2. "We have no choice" - Sought treatment when unable to cope - Admission to hospital as a last resort - Agreeable with the use of restrictive practices in the hospital - Police were called to manage the behaviours	1, 2, 4, 5, 6, 7, 8, 9	**FC 2:** "because last time she stayed with my mother, her grandmother, she became aggressive. She likes to beat my mother until became police case. Then after that they called the police and government agencies…" **FC 3:** "a number of times when he was violent. Stayed here one or

			two wks." **FC 6:** "He used to start hitting himself; he hit his father and hit me. So a lot of things happened. Then after some time we decided... Then finally I thought, not for us, it's for his own safety…" **FC 9:** "…after three weeks I took him back but his behaviour woah…was scary and scares me so I brought him back. He was supposed to have home leave for two weeks but i brought him back the next day because the nurse used to call us and ask how is his behaviour and i said his behaviour is still the same like he did before. So she suggested to take him back. So i brought him back, it's on and off…"
	3. "This is God's gift" - It's my responsibility to care despite the challenges faced - Prioritise my family member's needs before my own - I view myself as an advocate, not just a parent	1, 2, 3, 4, 6	**FC 3:** "Must love him. If you don't love him, how are you able to handle *(his behaviours)?"* **FC 4:** "it's my duty; he's my son. I also don't want to let him go. If no one wants to accept him, I have to accept him cos he's my son." **FC 6:** "I kept on telling them what he likes, what he doesn't like, what upsets him, what irritates him. I kept on telling, telling you see; so the thing is all his characteristics I have already shared with them."
Some services are better than others	**1. Staff need knowledge, skills and a warm heart** - Seeking to understand them - Knowing how to manage	1, 2, 4, 6, 7, 8, 9	**FC 1:** "Patience. They need patients and they need to empathize. I think you also need to know these people. Some sort of training to

	emotions and being patient - Having the relevant skills and knowledge - Having passion for the job - Helping to "control" the behaviours - Contrasting staff in mainstream and specialised services - Healthcare professionals treat us better than the public		know." **FC 2:** "yeah, passion. If not, you also cannot take care. Last time I also cannot understand." **FC 4:** "…they need qualifications too; not easy to enter. Then basically, kindness; cos they must have this ability when taking care of or teaching this kind of children." **FC 7:** "They have to understand them. This type of people, they have their moods sometimes. They don't work fast." **FC 9:** "They need to have an understanding of ID and autism and how to react to situations…and be compassionate..."
	2. Bio-medical treatment approach - Use of medication to manage behaviours -> helpful/not helpful - Rejection of the diagnosis - Dissatisfaction with consultation time - It takes time to get used to non-pharmacological approaches	2, 3, 4, 5, 6, 7, 8, 9	**FC 2:** "Doctor gives her medicines. It's not like the last time… But now she's... not say no more, still have but when she's alone. Last time she's very aggressive, warded in the hospital." **FC 4:** "Dr suggested and gave me choices. They have injections and asked which one I preferred… he suggested this tablet for my son. It's very small like a flu tablet but the effect is very strong and is suitable for his body weight. So I said ok will take that one." **FC 5:** "His temper is in the afternoon; during the day, his

			temper is bad. At night, he takes the medicine and sleep; so no temper. Best is to have a medicine to be taken in the morning to help him to cool down." **FC 8:** "Private GP, I always go for the medicine, Risperidone, only . Make him sleep. Before I go see the doctor, he 24 hours he won't sleep. He just wake up only, make noise, shout."
Public reaction – "If they make a noise, people are scared" - Public reaction focuses on disability - Public may not know how to interact with them - Positive experiences - Negative perceptions from employers Excluded from the society if they are unable to work Experiences of family member being bullied - Keeping family member at home, out of sight - Public becoming more tolerant - Mainstream services don't provide good service - Stigma discourages me to seek help		1, 2, 3, 4, 5, 6, 7, 8	**FC 1:** "…when she did something that offends somebody, that person might get angry. Without realizing that she's slower, she cannot respond the way... Yeah there were some incidents." **FC 2:** "Some people just shout. You can see people's face, sometimes they don't like this kind of thing. Don't like, what can be done, cry, cry, shout, shout. They can see this is not the normal." **FC 4:** "Everybody will look; that's very common. They like to look; why this boy like that? Some people will go aiyo (react negatively) when he bangs on things. But to me I'm used to it; as I've seen many people like that." **FC 7:** "I can see that when she walks past, everyone will take a look at her because she doesn't look normal. In the past was worse when she walked with her hand so side by side."

Worries and hopes for the future	**1. What will happen to him when we pass on?** - Desire my family member to become 'normal' - Hopes that other family members will become more involved - Considering residential? care - Difficulties with arranging future care - Not ready yet to make future plans - Worries that my family member will not adjust well after I am no longer around - Being protective towards my family member	1, 2, 3, 4, 6, 8, 9	**FC 2:** "I don't have any plans. But if anything happens to my daughter, let's say cannot talk, cannot walk, cannot go out. I told my other daughter...I sometimes ask her to stay with her sister but she doesn't want." **FC 3:** "We are Christians and we believe in leaving such things to God. But we also can't be lazy and not be bothered; we have to do our part. But we believe that we leave things up to God in the end." **FC 4:** "…what I know is if I'm no longer around, let's say I passed on; everything I've already told and passed to my sister. Cos my sister is the one who helped me a lot." **FC 9:** "I want professional staff. Family changes. They are good this year but the next few years down the road... family change, people change. I rather have a professional body looking after his personal things, his needs and all that.. At least a home..."
	2. "I want my son to be independent" - Attempting to integrate my family member into the community - Opportunities for independent travel - I am reluctant to focus on social interactions - The importance of work	1, 2, 3, 5, 6, 7, 9	**FC 1:** "Employment... I don't really think through. I don't see how it would help. What can she do? You know what i mean? I know from my experiences with the other parents, they also find it.. the children when they go out, they may get a working stint for a while then after that, they are sent back." **FC 4:** "My hope is that he can overcome things because he cannot adapt to changes well.

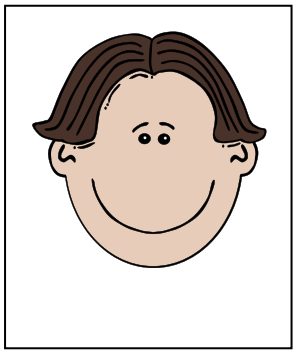
			Make sure he's happy for himself. So make sure as he grows, let say if I'm no more in this picture, to make sure he can overcome things." **FC 5: "**Help me by helping my child find a job but unable to find one currently. It has been like that for a few years." **FC 6:** "I also don't want him to stay at home. I want him to go somewhere to learn something and to expose him to things in the outside world."

Appendix 14: Simplified Information Sheet and Informed Consent Form (Links to Chapter 7 and 8)

Protocol Title:

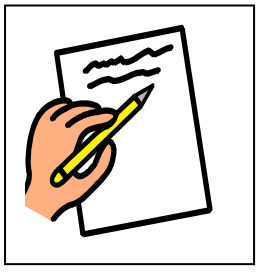
Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

Information



There is a man called Jon

Jon studies at Birmingham University



Jon is doing some research

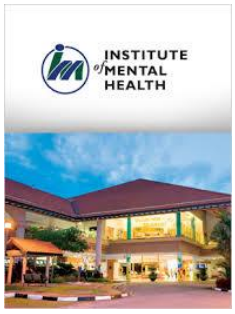


Jon would like to talk

Jon would like to talk to

- 

  People in Singapore 

- 

  Who are receiving care from IMH hospital

- 

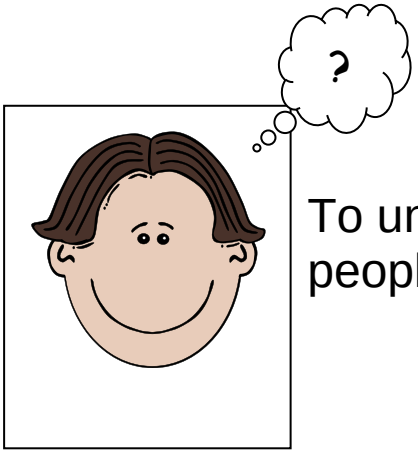
  Ask them about the care they receive

- 

  And what makes a good/bad doctor*

  (Substitute * for any healthcare staff)

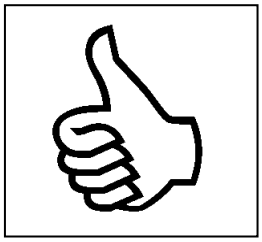
Why is Jon doing this work



To understand what you think about people caring for you

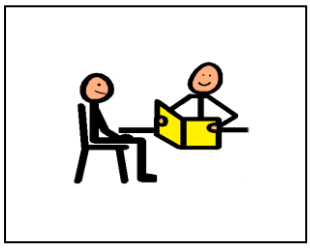


To help people to take care of you better

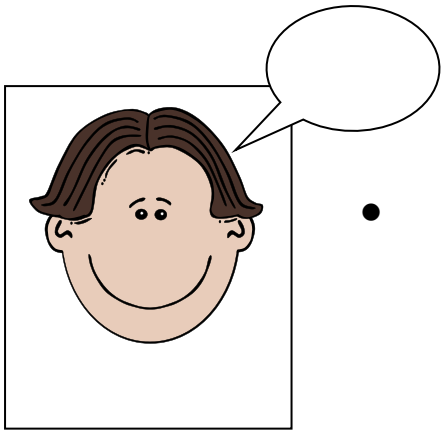


This is to help make better treatment programmes for people who are getting care at the hospital

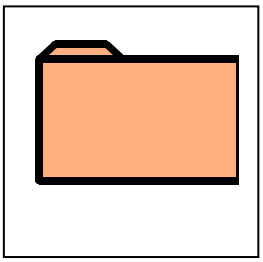
Working with Jon



Jon will come to hospital to talk to you



- Jon will ask you questions about the care you receive
- Jon will ask what you like or don't like about the people taking care of you
- Jon will ask you how people can take care of you better



There are no right or wrong answers

It will not change your treatment and therapy plan or your treatment

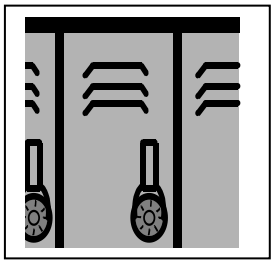
Working with Jon



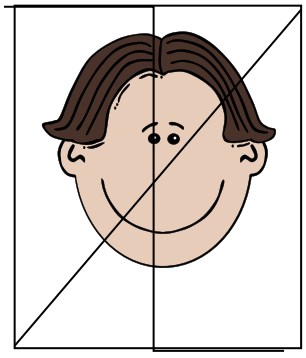
Jon will record what you say to him on a tape



This will help Jon remember what you have said

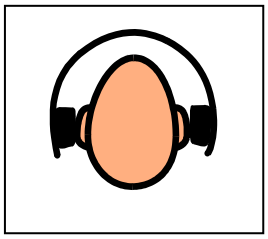


Jon will keep the tape locked in a cupboard



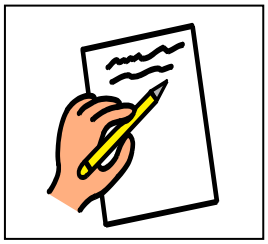
Jon will be the only person to listen to the tape

Working with Jon



After you have spoken to Jon

Jon will listen to the tape again



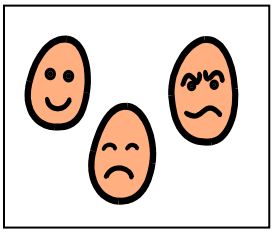
Jon will write down everything you have said



Jon will not tell anyone your name

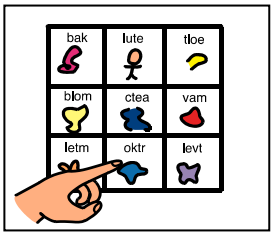
When Jon has listened to the tape he will destroy it

What if I get upset



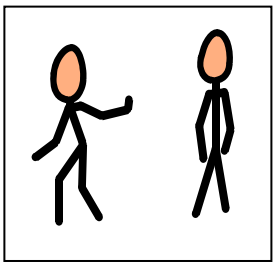
Jon will have some pictures to help you

say how you are feeling



You can point to the pictures

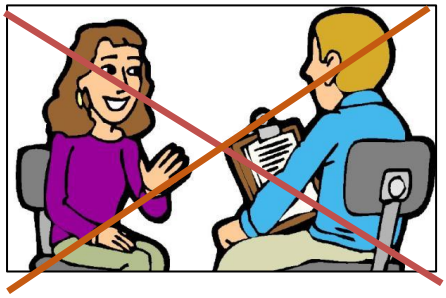
You can tell Jon if you want to stop



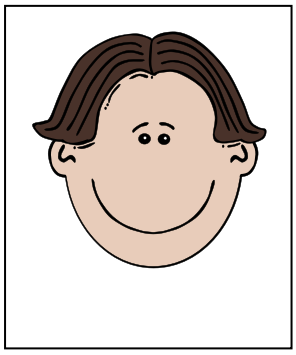
If you feel upset, it's ok to leave the room

It's ok to have a break

What if I am unhappy with the interview



You can stop the interview



You could talk to Jon



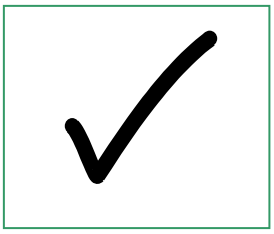
You could talk to psychology staff

You could talk to a member of staff

(*Name provided will be the principal investigator for this study)

Do I have to talk to Jon

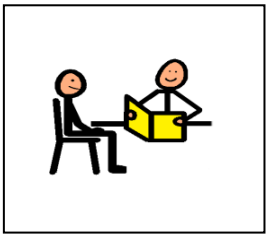
It's up to you. You can decide.



If you say **yes**



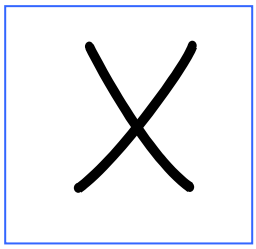
You sign a form to say you will talk to Jon



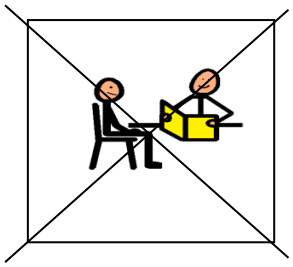
Jon will make a time to come and talk to you

Do I have to talk to Jon

It's up to you. You can decide.



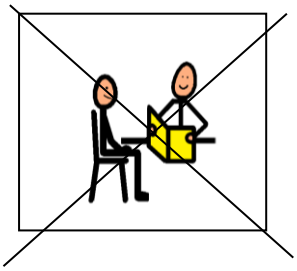
If you say **no**



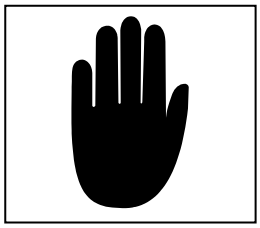
Jon won't come and talk to you

It is OK TO say "no"

What if I change my mind

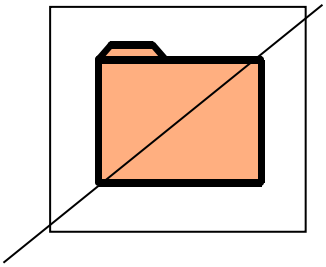


It is **OK** to change your mind



If you say “yes”

you can say “no” later



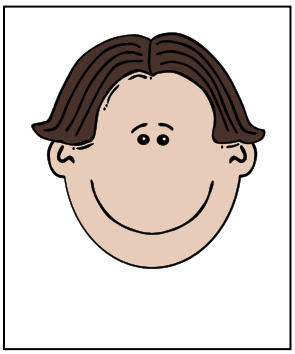
This will not affect your treatment plan.

You won’t get into trouble

It’s up to you.

It’s your decision.

Who can I talk to about my decision



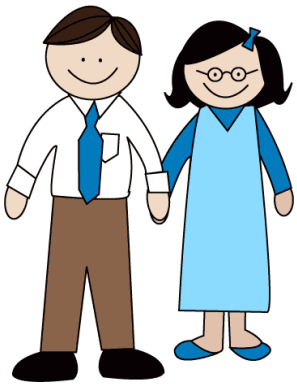
You could talk to Jon



You could talk to a member of staff*

(*Name provided will be the principal investigator this study)

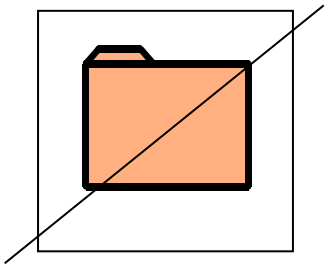
You could talk to psychology staff



You could talk to your family member*

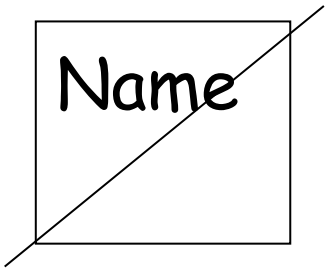
(*Substitute name of family member if necessary)

What next



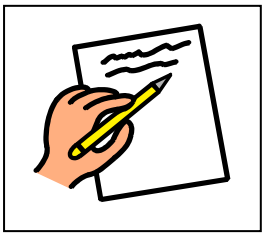
What you say to Jon will not change

your care plan

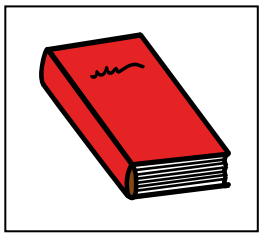


Jon will not use your name

no one will know you have taken part



Jon will write down what he has found out



This may get written in a book

What next



You can keep this booklet in case you want to read it again



Do you have any questions about what I have read to you?

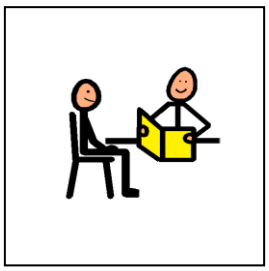
Now I'm going to ask you some questions just to see if I have explained this OK

CONSENT FORM

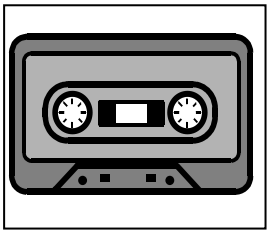
Protocol Title:

Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore

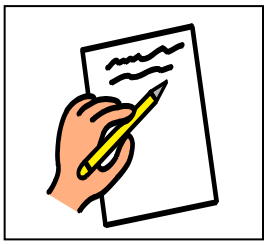
Put a tick in the box if you agree



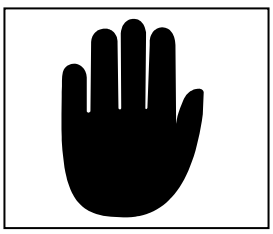
Jon can talk to me about my care in hospital ☐



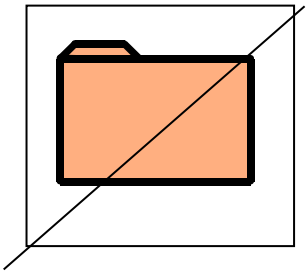
Jon can record what I say to him on a tape ☐



Jon will write down everything you have said ☐



I can say “no” if I don’t want to talk to Jon ☐



I can say “no”

It won’t change my treatment and therapy plan

☐

I can say “no”

I won’t get in trouble

☐



Please sign your name here

Name of Participant:

Date:

Translator Information

The study has been explained to the participant / legally acceptable representative in

_____ by _____

<insert language > *<insert name of translator >*

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of his / her participation in the study.

_____	_____	_____
Name of Investigator / Person administering consent	Signature	Date

Appendix 15: Assessment of capacity to consent (Links to Chapter 7 and 8)

1. Do you have to take part in this study?

Answer:

Correct answer: NO

2. What will Jon talk to you about?

Answer:

Correct answer: MY CARE IN THE HOSPITAL, PEOPLE TAKING CARE OF ME, ETC

3. Will Jon use your name in his report?

Answer:

Correct answer: NO

4. Can you change your mind later?

Answer:

Correct answer: YES

If the above questions are answered correctly:

5. Will you let Jon talk to you?

Answer:

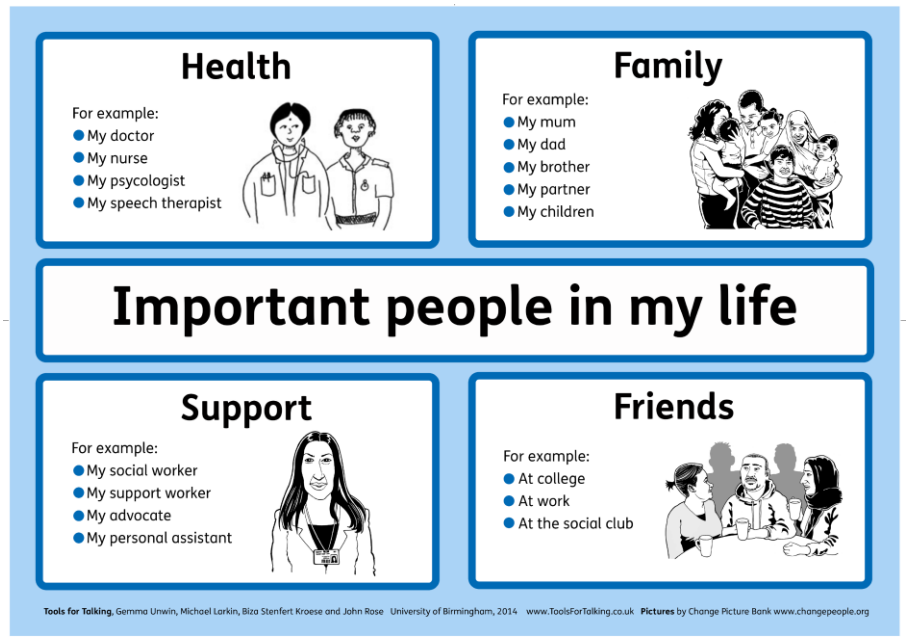
IF YES, ASK PARTICIPANT TO SIGN CONSENT FORM

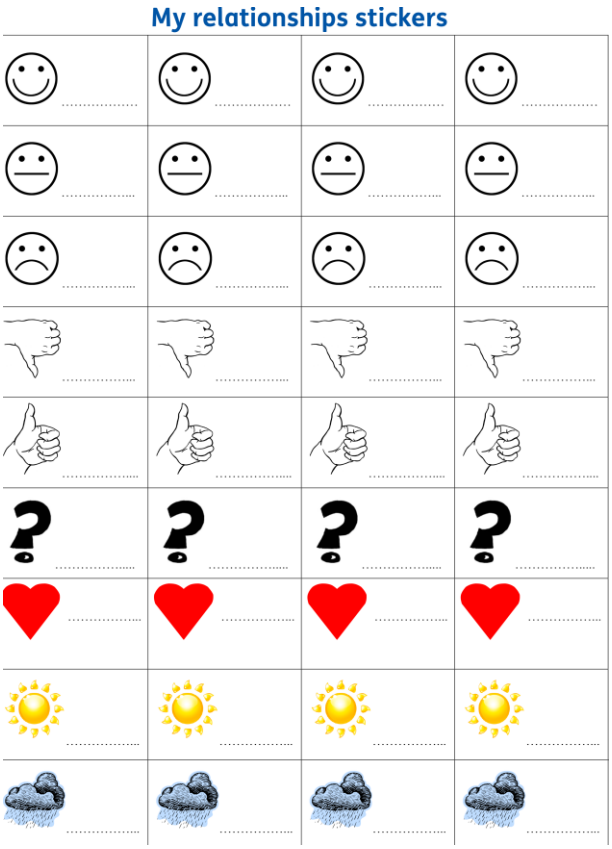
INFORM PARTICIPANT THEIR DETAILS WILL BE PASSED TO JON

Appendix 16: Activity for service users during interviews or focus groups (Links to Chapter 7 and 8)

During these activities, I will ask you to do some simple tasks.
I will also ask you some questions.
Feel free to say what comes to your mind. There are no right or wrong answers.

Activity 1







Instructions for the interviewer

1. Explain that the activity is to help participants think about the important people in their life and their relationships with them.

2. Show the 'Important people in my life and my relationship with them' video. https://www.youtube.com/watch?v=uqCmYP7N5VE&feature=youtu.be. Substitute the video with pictures or using simple words to paraphrase the content.

3. Check the participants know what the topic is to discuss, ask whether they have any questions, which parts were relevant to them and what it meant to them.

4. Explain the activity:

a. Read out some of the examples of people who might be important in each section.

b. Each participant completes an A3 or A4 worksheet (hand round the sheets). Participants may need help writing on the worksheets and stickers.

d. Ask the participants to go through each section to write the names of the people who are important to them. If there are other family members around, they can help participants to identify people. You can substitute some of the names for easy understanding e.g

Staff listed under Support

1. *My support worker → My training officer*
2. *My advocate → My job couch*
3. *My personal assistant → My center teacher*

Places listed under Friends

4. *At college → School/university/ITE*
5. *At work → Job training center*
6. *At the social club → At day activity centre/center/school*

e. Participants then put a sticker next to each name to describe that relationship. Show the stickers to the service user(s), explain that there are lots of different stickers, they can mean lots of different things. Describe some of the stickers but try not to provide your interpretation of what it means. There are two sheets of stickers, the first sheet contains a more familiar set of images; you and the service user may like to use that sheet only.

f. There are also blank stickers so the service user(s) can draw their own picture.

g. A word can be written on the sticker to further describe the relationship. Discuss this with the participant to identify an appropriate word.

h. Multiple stickers can be placed for each person.

i. If anyone asks, there are no set definitions of the stickers, they can mean different things to different people.

5. Ask whether anyone has any questions before starting the activity

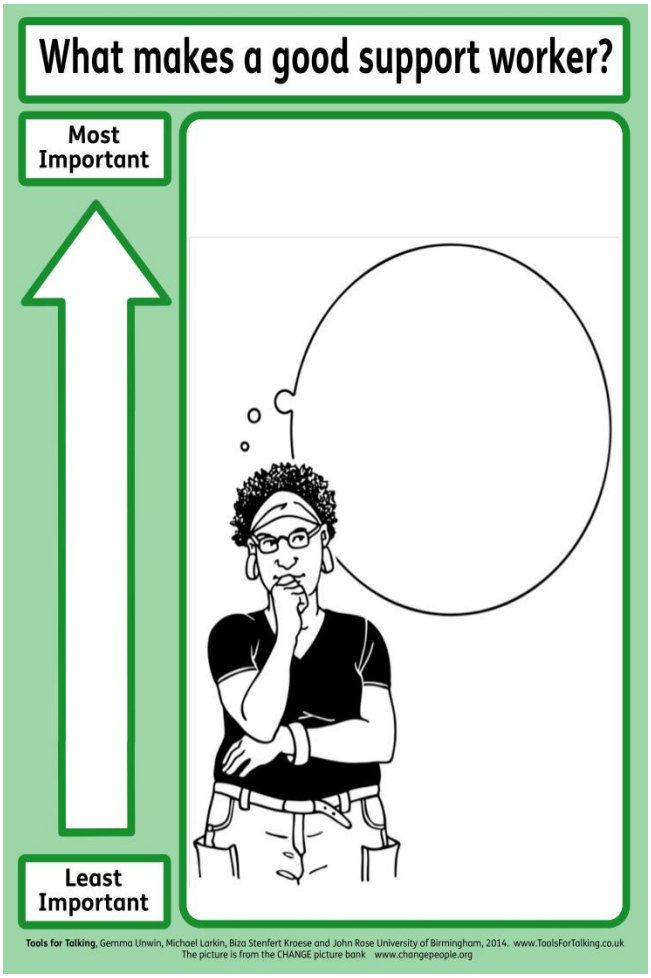
6. When writing on the worksheets, ensure enough space is left for the stickers.

7. Encourage discussion and verbal explanations throughout. Ask the participants to explain what the sticker means to them and what it represents in relation to their relationship with each person named on the worksheet. Help participants to write a word to describe their relationship on each sticker.
8. Group discussion could follow the activity if it has been completed by participants at the same time

Main interview questions (aided by prompts and visual cues)

- What do you do with that person on a normal day?
    - Prompts: How does he/she help to take care of you? What activities do you do with him / her?
- How do you feel when you are with the person?
    - Prompts: Ask about their feelings, how they behave and communicates with the person, can compare feelings and behaviours across different domains on the worksheet

Activity 2



What makes a good support worker activity cards

Is like a friend	Tells me things about their life too
Checks up on me	Likes the same things as me
Helps me to do things which I enjoy	Is male / female like me

Funny	Tells me what to do
Gets on well with my family	Understands how I feel
Decides what is best for me	Is good at their job

Always does the things they say they will do	Does not make fun of me
Knows my support plan	A good listener
Kind	Helps me to change the things I want to change

Has the same religion as me	Supports me when they feel like it
Helps me with things that I can't do	Respects the things that are important to me
Speaks for me	Is easy to talk to

Helps me learn	Does not ignore me
Can be trusted	Enjoys working with me

Instructions for the interviewer

1. Explain that the activity is to help participants think and talk about what makes a good support worker or a good health care worker

2. Show some pictures of health care workers, describe their roles and responsibilities to the participant. You may wish to use the previous activity to guide participants to narrow the focus on their health and the people involved.

3. Check the participants know what does a health care worker does, e.g doctor, nurses, allied health professionals. Ask whether they have any questions.

4. Explain the activity:

a. Direct participants to the poster

b. Explain that the activity is to place the cards on the arrow. The higher up the card is placed, the more important it is.

c. The cards have things written on them that might or might not be important when thinking about a good support worker. Different people might have different opinions. Emphasise that it is fine if people have different ideas.

d. In groups, participants take it in turns to take a card from the pile and put it on the arrow to indicate the importance of the attribute to them. There are blank cards to write additional attributes, either positives or negatives that are mentioned or are missing.

5. Ask whether anyone has any questions.

6. Ask the first participant to take a card from the pile and show it to the group, make sure you read it out clearly, so the group can hear, and provide explanations, if required. For e.g

a) Is good at their job → Is good at helping me
b) Gets on well with my family → Gets along with my family
c) Knows my support plan → Know about my treatment/therapy plan
d) Can be trusted → I trust him or her
e) Does not ignore me → Gives me attention

8. Ask the participant to place the card on the arrow.

9. Ask the person to explain their decision.

10. Repeat the process until all the cards are placed on the arrow, asking each participant to explain their decision and exploring the ideas of others through discussion. It is not essential that all the cards are placed, exploration of ideas is more important

11. If time allows, ask the group to generate their own attributes, either positive or negative, write them on the blank cards and place them on the arrow.

12. Cards can overlap and can be moved at any time. It does not matter if most of the cards are placed at the top.

Main interview questions (aided by prompts and visual cues)

- What sort of things do you like your health care worker to help with?
    - Prompts: Taking medication? Help you feel less/more sad/happy/angry? Take part in any activities?
- What do you like/do not like about your doctor/nurses?
    - Prompts: What it is like to see your doctor? How do you feel about your doctor?
- Are there any other things/issues you like to be different?
    - Prompts: For example, when they talk to you? When you want to ask them questions?

Follow-up questions if time permits

- What do you know / understand about your condition?
    - Prompts: Have anyone explained to you about your condition? How do you feel after hearing it?
- Here's a logo for [hospital], share with me about what it is like?
    - Prompts: Anyone treat you differently? How did you find your stay in the ward? What do you like / don't like about coming to the hospital? Have anyone explained to you about your condition?

If participants stay in residential settings, e.g community homes

- Here's a logo for [residential home], share with me about what it is like to stay there?
    - Prompts: How did the staff/workers treat you?

(Can revisit the first activity again to ask about their relationships with different individuals in the residential setting)

Exploration of future

- What do you like / don't like about your life?
    - Prompts: What kind of changes you like to have? What do you like to do in future?

(may wish to provide specific time frame or situation if participants are unable to understand, e.g what do you like to do when you are well / after you return to stay with family / in 1-2 years time?)

Resources are adapted from www.toolsfortalking.wordpress.com

References

Unwin, G., Larkin, M., Rose, J., Kroese, B. S., & Malcolm, S. (2016). Developing resources to facilitate culturally-sensitive service planning and delivery–doing research inclusively with people with learning disabilities. *Research involvement and engagement*, *2*(1), 17.

Appendix 17: Pilot Study with the people with ID in the UK (Links to Chapter 7 and 8)

On 23 March 2018, I met with a group of men with mild ID and MH problems in Telford to carry out a pilot study of Activity 1 and 2 in Appendix 15. There were about 20-25 men who came for the session. The session started off with basic introduction of their names and they gave brief account of their MH experiences

Regarding Activity 1, most of the men understood the instructions before carrying out the activities. We did the activity as a group and there were discussions about the support they received from their carers and healthcare professionals. Some shared that they lived alone and receive support from care staff, others shared about the friendships that they made when attending group therapy sessions. There were a few that talked about having part-time work which they enjoyed and found a sense of fulfilment

Regarding Activity 2, the men were able to understand the different attributes and categorized them according to their preference. Some were willing to disclose about their experiences receiving MH treatment and expressed their feelings. Most of them preferred someone who listen and treat them with respect. There was also discussion about having trust with HCPs and being comfortable to share their feelings too. A few spoke about their experiences regarding how healthcare professionals treat them when they received MH services and the changes they would like to see in the services.

Lastly, I conducted a Q&A session with them. The men were curious and keen to know about the study and Singapore. I shared with them briefly about the research and how MH services are provided to people with ID. I also shared about my experiences of living and working in Singapore, and how my research will help to improve the services.

Appendix 18: Example of a worked interview transcript (ISU) (Links to Chapter 7)

Emergent Themes	Original Transcript	Exploratory Comments
Identifies nurse as main professional – able to recall her name (1)	Is it? Oh.. the indian doctor lah huh. Ok Then you got any nurse or not? That ah.. Any nurse that take care of you? I think this ah… sa…. what is the name? S_G S_G lah. The nurse lah. Ok..	Identifies nurse as main professional carer taking care of him in the long stay ward
	Then any other people? Any other people you work with? Psychologist or I think hmm… ah….. ah this ah… ah…. Psychologist or? Some older nurse	Identifies the psychologist for behavioural support
Comes from large family (2)	Your brother lah. Older brother? Older brother and me lah. How many siblings do you have? Five. 5 people I see….? Orh…Then your parents? Parents I think two. mother and father Are they around still? At my holland avenue road there. Then other thing is my sister. Older sister I think come from Sembawang	Has other siblings but not in regular contact any more
	Support leh? Any support in helping you? In your…?	

Engages in activities in the long stay ward (2a) Examples of activities that he engages in (3) Shares how he came to be warded (4) Main job is to find a job to work (5) Shares about his previous life (6)	Some lah. Some origami. Oh! Who is the teacher at origami? My teacher I think Any other thing? Any other activity you do? Other activity I think… ah… sweeping the floor Sweeping the floor arh? Then who is helping you to sweep the floor? I think … aye… mao whye Mao why ah. I put mao. Then you here any friends? Aye… Then how did you come to this place huh? My friend bring me to the No. 8 double estate there and sleep What do you hope from staying here? I also want ah. Find an ideal job Oh. Ideal job lah. To find work lah. Then you stay here 5 years already? 5 years What happened the previous time? Got a bit participation in factory work Then what happened? I like to what ah.. I want to become a joker like that. Also. Like to eat goreng pisang Then after that? Then after that I think.. I want to… know how to make kite for the. Layang. And.. and help.. help to do a bit of simple jobs	Spends his time doing origami and sweeping the floor Identifies having friends Said that he was brought by his friend as he was sleeping outside (homelessness) Describes his stay here as looking for ‘work’ Previously worked before admitting into the hospital Shares that he did not take his work seriously

Views that important to find work as it gives him a sense of purpose (7) Views his stay temporary (8) Learns how to play a new game (9) Misses his outside friends (10) Shares that he is able to do the activities that he likes when outside (11) Wants to be 'productive' for society (12) Appreciative of the doctors' efforts and services (13)	<u>Then how come you come here leh? Become come here</u> Cos I want.. I want to.. to find a bit of work <u>Then you stay here how you find the stay here?</u> I think got a temporary place of settling down. <u>Then down here you like to stay here?</u> I like to stay here and know how to play a bit of mahjong. <u>Is there any thing that you miss here?</u> I think I miss my mother. Old class teacher. <u>Oh.. old classmates there lah? New town secondary school lah. Ok. Anything else you miss outside mah?</u> At outside, I got a bit of this… ah… Baking a bit of stuff. Cooking. I like to take up .. take care.. national service <u>Then you here, the Indian doctor, how do you find him? Is he a good…?</u> Very very appreciate. <u>Here are some pictures. You help me look at it and tell me how is your relationship. You just have to look at it and tell me how you feel? How do you find the Indian doctor? Can you show me? Find which picture you think is good?</u> Clock. Clock.	Keen on looking for work opportunities Strong desire to look for work ➔ Views it giving him a sense of purpose Views staying in the long term ward temporary -> main focus is to look for work Having enjoyed recreation activities in the ward ➔ Plays mah-jong ➔ Keeps him occupied and happy to stay there Missed his friends outside of the ward environment Also shares that he missed to do some of the activities that he likes to do when he is outside Desire to be 'productive' in the society - Wants to take up conscription as a way to contributing to the society Appreciate the doctor's services

Views his healthcare professionals 'watching' over him (14) Nurse provides him with outside food (15) Shares that the nurse is concerned about him (16) Views that the nurse talks to him nicely (17) Yearns to be able to take care of himself (18)	<u>What does the clock represent?</u> Represent some…. Give me record one…. Guinness record wan. <u>Then the nurse leh? Do you like the nurse?</u> XX. I think… ah.. buy me some curry puff to makan. <u>Oh she give you curry puff to makan lah.</u> <u>How do you find her? Is she very good or is she no good to you?</u> Some Chinese people like that. But the… The nick name is called X. She is concerned about me. <u>Take care of you lah? Oh.. how she show concern for you?</u> She will help me do her best; aspects. She is concerned about me. <u>Is there a photo here that can represent her concern?</u> Don't everyday scold and shout. <u>Oh. So she never shout lah.</u> And don't try to scold vulgarities. <u>She also never scold lah oh… ah.. ok.. ok…</u> And and and I want to plant some flowers inside the garden <u>Then you stay here how is it? People take care of you, good or not?</u> They take care of me. A bit.. Liang shi – have to take care of myself *(Transcript continues on)*	Clock – recording his vitals, checking on him (watching) over him to make sure that he is okay Nurse – buys food for him Views that the nurse is concerned about him ➔ Views that she looks after him in his best interest, doesn't scold and shout ➔ Does it mean that the staff in long stay ward does scold other patients? Nurse allows him to do some of the activities that he likes e.g gardening Shares that he has to depend on myself - Yearns to be independent? - Have some sense of understanding that he needs care and would find it ideal if he can be able to take care of himself

Appendix 18 (Continued) – Example of a worked interview transcript (ISU) (Links to Chapter 7)

Theme no 1: Experiences of having mental health symptoms

- Making sense of mental health symptoms (34)
- Shares that he has difficulties with emotions (35)
- Does not like to take medication (38)
- Describe the side effects of medication (dizziness, fatigue) (39)
- Shares that he does not like arguing with others (40)
- Views it a struggle to manage his emotions (41)
- Shares how he came to be warded (4)

Theme no 2: Experiences of staying in long stay ward

- Identifies nurse as main professional – able to recall her name (1)
- Views his stay temporary (8)
- Appreciative of the doctors' efforts and services (12)
- Views his healthcare professionals 'watching' over him (14)
- Nurse provides him with outside food (15)
- Shares that the nurse is concerned about him (16)
- Views that the nurse talks to him nicely (17)
- Knows his friend for 4 years (23)
- Views himself caring for his friends (24)
- Views the hospital food in the ward 'not nice' (25)

Theme no 3: Yearns for his past life

- Shares about his previous life (6)
- Misses his outside friends (10)
- Shares that he is able to do the activities that he likes when outside (11)

Theme no 4: Activities to engage him in the ward

- Engages in activities in the long stay ward (2a)
- Examples of activities that he engages in (3)
- Learns how to play a new game (9)
- Finds it boring and tries to keep himself busy (26)
- Does origami with assistance from staff (21)

Theme no 5: Family support

- Comes from large family (2)
- Shares that he miss his mother as his brother only visits him (19)
- Views his uncle treats him with respect (20)

Theme no 6: Desire to be 'productive'

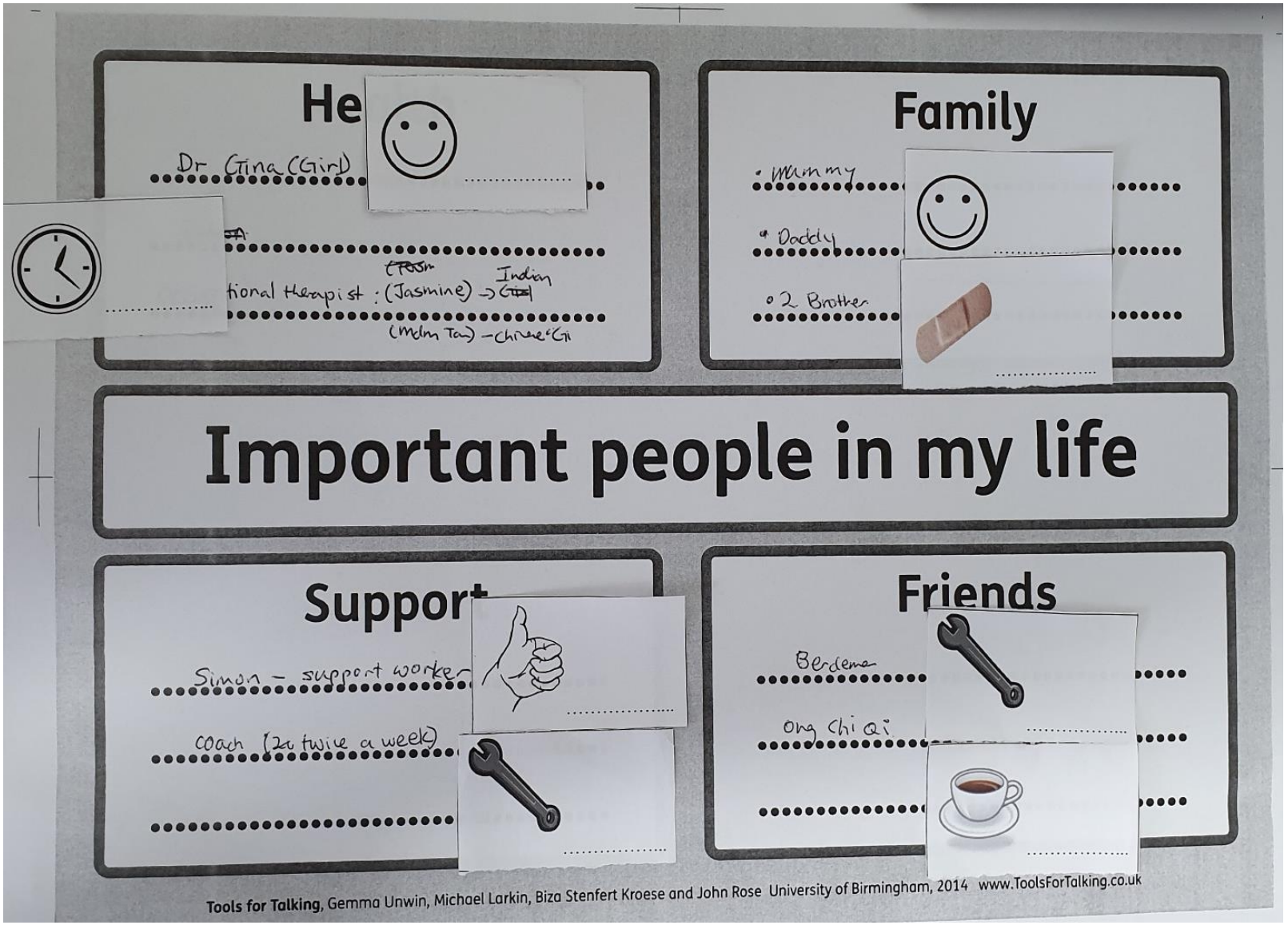
- Hopes to study and goes to university (27)
- Main job is to find a job to work (5)

- Wants to do like what other people is doing (28)
- Views work as providing a service to others, making himself useful (29)
- Views that important to find work as it gives him a sense of purpose (7)
- Yearns to be able to take care of himself (18)
- Wants to be ‘productive’ for society (13)
- Wants to do more ‘challenging’ work instead (22)

Theme no 7: Attributes of healthcare professionals

- Wishes healthcare professionals to be compassionate (30)
- Views that healthcare professionals ‘control’ aspects of their lives (31)
- Wants healthcare professionals to treat him nice with respect (32)
- Wants healthcare professionals to tell him what to do (33)
- Having healthcare professionals to enjoy their work and have similar interest (36)
- Views healthcare professionals as a ‘listening’ ear for counselling or advice (37)

Appendix 19: Example of activity with ISU (Links to Chapter 7)



What makes a good healthcare worker?

Most Important

1. Understands how I feel
2. Does not make fun of me
3. Can be trusted ✓
4. Does not ignore me
5. good listener ✓



Least Important

Tools for Talking, Gemma Unwin, Michael Larkin, Biza Stenfert Kroese and John Rose University of Birmingham, 2014. www.ToolsForTalking.co.uk
The picture is from the CHANGE picture bank www.changepeople.org

Appendix 20: Table of themes for ISU (Links to Chapter 7)

Main Theme	Sub-themes	Participant	Example of quotes
Awareness of mental health problems - *"Because I a bit… My brain…craziness…"* - how I came into the service - I'm a 'troublemaker' /aggressive - managing emotions - don't like taking medication - I want to stay here		3, 5 and 6	**ISU 6:** "…alcohol problem…my wife sends me here" **ISU 5:** "Hear too much… party of doubts in mind"
Yearn for a life outside the ward - ***"I want to go home"*** - hospital is "noisy" - stay is "temporary" - desire to be 'normal' - Yearning for home and past life		3, 4, 5, 6	**ISU 3:** "…No. He wishes to go back home…The other patient also makes fun of me." **ISU 4:** "Don't like to stay here (crying)." **ISU 6:** "They shouting shouting…nurses tie them up" **ISU 5:** "I think I miss my old class' mother. Old class teacher"
Interacting with other people	**Family involvement –** **"My family won't come fetch me"** - family members don't visit	1, 3, 4, 5 and 6	**ISU 6:** "wife seldom come…she's sick"

	- I miss my family - my family treats me with respect - how are they coping without me? - other patients make up for loss of family		**ISU 5:** "…miss my mother…" **ISU 1:** "No, only one friend…the person is from my ward…keep me company"
	The way healthcare professionals treat me - healthcare professionals are there to look after my health - they are kind - they are rude - they are scolding - respect versus authority	1, 2, 3, 4, 5, 6	**ISU 4:** "Not happy with the doctor, don't speak to the doctor" **ISU 3:** "…make fun of me…everytime nurse scolds…" **ISU 6:** "ya, the doctor's kind…"
Finding purpose - activities and odd jobs - social interactions - Being of service to others, being useful - Being independent		2, 3, 5, 6	**ISU 3:** "He's my friend…yeah he's my friend." **ISU 6:** "…do work…do little jobs…one month one time pay" **ISU 2:** "work together with friends…use fork and spoon with therapist"

Appendix 21: Example of a worked interview transcript (OSU) (Links to Chapter 8)

Emergent Themes	Original Transcript	Exploratory Comments
Support from family (1) Satisfied with services (2) Finds service helpful (3) Mainly seek healthcare professionals' advice (4)	J: Write down the word to describe why you chose this picture. What is the word you use to describe this? P3: Love. J: If you don't want to write also can, later I ask you, you can just tell me. If you need more words to describe, we can talk about it later. P2: This one, mother, father love me. J: Yes, can write mother, father love you. J: How about the thumbs up? Why did you choose thumbs up? P2: Thumbs up means good (towards healthcare professionals). J: Why did you choose good? What is good about them? Is it kind? P2: Helpful.	Describe her parents as 'loving' Acknowledge support from family carers – parents Satisfaction in the specialist services

Healthcare professionals provide advice on social skills (5) Healthcare professionals showing care and concern about his health (6)	J: You can write there helpful at the thumbs up. P2: Can say helpful or not? The OT is it can be helpful? J: Yes. In what way are they helpful to you? P2: They helping me. They tell me how to do it. How things can be solved and done. J: Ok just put there helpful. J: Ok so we go through now one by one. We will go through each of them, why do you choose smiley face? How is she a good doctor to you? P4: Because she explained the good things to me. J: What sort of things she explained to you? P4: Like good things you should do. Bad things you should not do. Like that. J: Is it helpful? These good things and bad things? P4: Yeah.	Acknowledged that the OT are more helpful ➔ More directive? Tell them how to solve things ➔ Help them by providing direct coaching ➔ Things – problems or situations that they encountered that they find difficult to solve? Healthcare professionals teaching him social skills ➔ Chose 'smiley' face ➔ Feels happy when he sees her ➔ Teaches what is appropriate for him to do and not to do

Expresses his wish to stay healthy (7) Activities that he enjoys (8) Sharing common interests with other service users (9)	J: Then for Ms XX, why is she important for you? P4: She wants me to keep fit and healthy. J: Ok, so she cares about your physical health. She focuses more on you keeping fit, makes sure you have enough exercise. P4: Yes. J: So, the heart, what does this represent for Ms XX? Why you chose the heart? P4: Because this one is healthy. J: Healthy. Is that something important to you? P4: Yeah. J: So not just mental health, but physical health as well is important, so exercises, going out and jogging. So have you been following what she said? P4: Yes.	Acknowledged that healthcare professionals' having their interests - Being healthy and fit - Uses the 'heart' to show that he agrees with healthcare professionals taking an interest in his health - Values his health and likes to do exercises Finds it importance to keep himself healthy and fit

States her preference that is different from healthcare professional's advice (10) Identifies parents as important people in his life (11)	J: So what do you do? What exercises do you do? P4: Running. J: Where do you run? P4: Jogging track. J: So anyone done any exercises? Have you done any exercises? P2: Me? I have also done some exercise. J: What exercises have you done? P2: Like exercise can be wall push ups. I have done exercises like swimming. J: Do you do them on your own or is someone teaching you? P2: On my own. J: What about you?	Examples of activities that he likes to do Similar interests with another participant that likes to do exercises - Swimming, push-ups Does not like to exercises - Adhere to healthcare professionals' advice even though she does not like to do them - Listens to advice from healthcare professionals despite her preference

Parents show care towards him (12) Able to have opportunities to celebrate special occasions with family (13) Agrees that he likes to spend time with his family too (14)	P3: I rarely exercise. But I always go OT and the OT will ask me to exercise. But I don't like. Very tiring. J: Ok normal, very tiring. Anything you want to ask about health? Don't have, we'll move on to family. So family, you put one brother and one sister, you chose the picture of a road. Maybe you can describe why you wrote the word leader. This is for your parents. So why do you see them as leaders? P4: Because my parents are important persons of the family. J: Do you see them frequently? P4: Yes. J: Then with your parents, what do you usually do with your parents? P4: Parents, they care for me. J: Any activities? What do you do with them? Do you go out? P4: Yes sometimes.	Participant 4 identifies parents being the important persons in their family - Sees them as 'leaders' -> likely they will make decisions for him which he will follow - Views them important as he knows that they made decisions based on his best interests - Identifies his parents caring for him Likes spending time with his family - Have opportunities to celebrate special occasions

Shares that she can express her choices regarding food on special occasions (15)	J: Do you exercise with your parents? Do your parents bring you out? P4: Sometimes only. J: Where do you go? P4: My parents they go different places. J: Where do they bring you? P4: Birthday celebrations. J: So birthday celebrations are important for the family? So how many of you for your birthdays your parents bring you out to celebrate? P2: On my birthday, my mum brings me out. I also go out on my birthday. J: You go out also? P2: Yes. J: So most of the time, for birthdays, your parents bring you out. Then how about you, your birthdays?	Similarly, another participant likes to spend special occasions with his family Examples of spending time -> eating at their favourite restaurants ➔ Able to exercise their choices on where they want to eat

Likes to spend his time socialising in the community, spending time with family (16) Importance of siblings (17) Confide in family (17) Talks to support staff whom he has a closer relationship (18)	P3: Sometimes. J: Where do they bring you? P3: Like eat at my favourite restaurants. J: For you, on your birthdays, what do your parents do with you? P2: My birthday go out and eat. J: Eat only? Other than eating? P2: What I do is eat for my birthday. J: Do they bring you to somewhere? P2: Places. J: Yeah places. P2: I go to Tampines (?). I also do things. I also go and eat and hang out. Eat at the same place and hang out. Also can do other things, celebrate and eat.	Having opportunities to socialise in the community ➔ Spending time with family ➔ Doing activities like any other family members would out ➔ Allowed to engage in social interactions Acknowledged the importance of his siblings -> Helping him

Important for staff to check on him and ask how he is doing (19) Support staff provides him work that gives him a sense of purpose (20)	J: So XX has siblings too, how important are they to you? Siblings. Why are they important to you? Why are your brother and sisters important? P4: My siblings also important to me because...because they help me too. J: When you have difficulties and need someone to talk to, who do you talk to? P4: Parents and also siblings. J: Is there any particular person that you talk to more? Maybe you talk to siblings about school and talk to parents about friendship; something like that? P4: Maybe talk about...the closest I talk to, you know, the case manager. J: Ok, you talk to the case manager? P4: Yeah, case manager. J: Oh he is not inside the pictures? P4: Yeah, he's not.	Confiding in his parents when he encountered difficulties However, for other difficulties regarding social situations, prefers to confide with support staff – case manager - Identifies him important to help him with managing difficulties relating to social situations, employment/school etc

	J: Is he important to you? P4: Yes. J: Ok, that's good. So anyone has any relatives? Don't have? Only father and mother. In terms of support, can you share with me what does Mr Wei Ya, the case manager, do with you when you see him? What does he do with you when you see the case manager? P4: He just ask me how I feel and all that. That's why they help me with instruction and give me work. J: So give you work and a sense of purpose? P4: Yes. *(Transcript continues on)*	Importance for support staff to check and understand how he feels - Mostly listen and takes instruction from them to help him in his life

Appendix 21 (Continued) – Example of a worked interview transcript (OSU) (Links to Chapter 8)

Theme no 1: Views towards healthcare professionals

- Satisfied with services (2)
- Finds service helpful (3)
- Mainly seek healthcare professionals' advice (4)
- Healthcare professionals provide advice on social skills (5)
- Healthcare professionals showing care and concern about his health (6)
- States her preference that is different from healthcare professional's advice (10)
- Healthcare professionals listening and solving problems (24)
- Healthcare professional encourages her (25)
- Activities that she does during the session with her healthcare professionals (26)
- Wants to continue seeing healthcare professionals more (27)
- Low frequency of contact with doctor (28)
- Negative feelings towards doctors (29)
- Views healthcare professionals 'helpful' in taking care of his health (39)
- Shares his experiences when he visits other doctors (40)
- Healthcare professionals listening to him (41)

Theme no 2: Family support

- Support from family (1)
- Identifies parents as important people in his life (11)
- Parents show care towards him (12)
- Parents take care of her (30)
- Views mother as more supportive (31)
- Perceives her father views her having low self-esteem (32)
- Identifies his mother as taking care of him (42)
- Seek his mother for help when he encounters difficulties (43)
- Importance of siblings (17)
- Confide in family (17)

Theme no 3: Able to express and carry out their wishes

- Sharing common interests with other service users (9)
- Able to have opportunities to celebrate special occasions with family (13)
- Agrees that he likes to spend time with his family too (14)
- Shares that she can express her choices regarding food on special occasions (15)
- Expresses his wish to stay healthy (7)
- Activities that he enjoys (8)
- Likes to spend his time socialising in the community, spending time with family (16)

- Able to participate in his interests i.e religion (22)

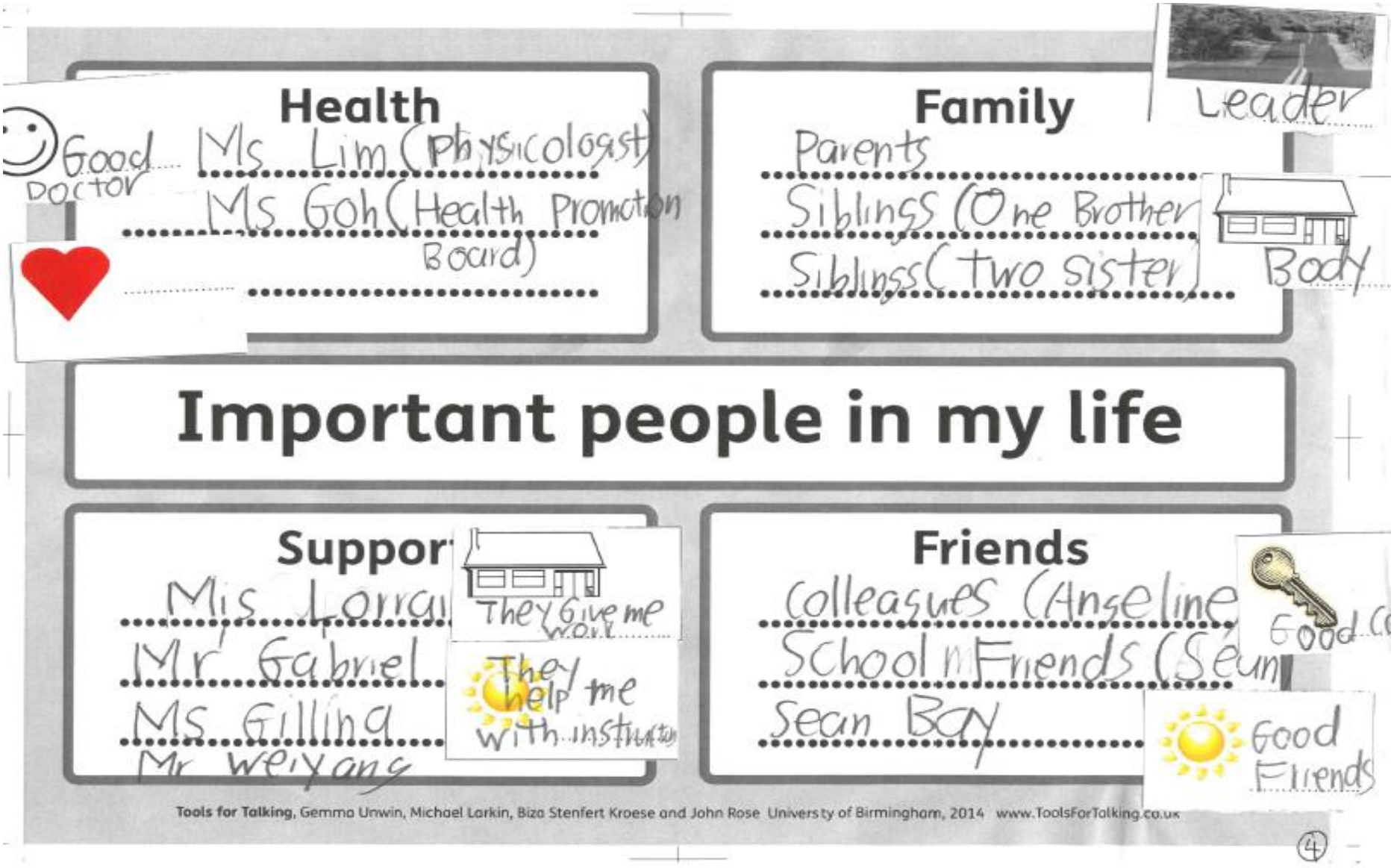
Theme no 4: Keen to engage in social interactions

- Supportive role of her friend (36)
- Reminisce about her friends in the past who have helped her (37)
- Wants to improve her social circle of friends (38)
- Having social relationships in his workplace (21)
- Wants to spend more time with his friends (23)
- Likes the courses because of friendships made (46)
- Having social interactions with friends, spending them with them (47)

Theme no 5: Engagement with community services

- Talks to support staff whom he has a closer relationship (18)
- Important for staff to check on him and ask how he is doing (19)
- Support staff provides him work that gives him a sense of purpose (20)
- Appreciates having opportunities for employment (33)
- Describes support staff as friendly (34)
- Support staff is concerned about her future (35)
- Finds helpful attending courses (44)
- Learning the skills and applying them (45)

Appendix 22: Example of activity with OSU (Links to Chapter 8)



What makes a good healthcare worker?

Most Important

1. Enjoys working with me
2. Is good at their job
3. ✓Can be trusted
4. Knows my support plan
5. ✓Understands how I feel



Least Important

Tools for Talking, Gemma Unwin, Michael Larkin, Biza Stenfert Kroese and John Rose University of Birmingham, 2014. www.ToolsForTalking.co.uk
The picture is from the CHANGE picture bank www.changepeople.org

Appendix 23: Table of themes for OSU (Links to Chapter 8)

Main Theme	Sub Themes	Participant	Examples of quotes
Sense of self – **"I feel angry with myself, I blame myself"** - low self-esteem - Blaming self - Trying to be 'normal' - Expecting recovery		1, 3, 5	**OSU 1:** "I cannot improve, I cannot do anything." **OSU 5:** "Broke down, fell down...couldn't feel anything, becoming disconnected from reality"
People who matter to me	**1. Family support -** **"Parents, they care for me** - family as main support - missing family - family advises	1, 2, 3, 4, 5	**OSU 1:** "Father is going hospital and for operation, he said that his leg cannot walk.. I feel so upset. Nobody talked to me." **OSU 4:** "Because my parents are important persons of the family…they care for me"
	2. Community support **"Open the door"** - supported employment - courses to learn new skills - community programmes - Feeling grateful for opportunities to train and work - support staff that help and guide.	1, 2, 3, 4, 5	**OSU 5:** "…He is the one that is helping me get a job, the agency is for people with intellectual disabilities and neurodevelopmental disabilities" **OSU 4:** "That's why they help me with instruction and give me work." **OSU 2:** "Another support is from my course; about what I'm doing in the course."

		3. Interactions with specialist mental health professionals **-support and respect** - negative experiences affect follow-up treatment - ideal attributes and qualities - non-pharmacological approaches - lack of discussion and collaboration - Appreciates the support and respect that they received from healthcare professionals to help them	1, 2, 3, 4, 5	**OSU 1:** "The doctor is angry, scold me for being angry" **OSU 5:** "Psychologist gave me suggestion and tips how to improve my behaviour, how to prevent aggressive behaviour, learn coping strategies. Those are the things that she gave me to do" **OSU 2:** "They helping me. They tell me how to do it. How things can be solved and done"
Choice and autonomy -"Just respect me" **-** Making life choices - Allowing contact with family - Religious freedom - Opportunities to spend special occasions with family - talk to me and treat me as an adult person - not using restrictive practices - Wants mental health professionals to respect their choices			1, 2, 3, 4, 5	**OSU 1:** "They tie me up they pull me like that until...they tie me from behind until all my legs..." **OSU 5:** "I can relate to someone which I know and listen to my problem, treat me like an individual" **OSU 3:** "…Like eat at my favourite restaurants with my parents"
Hopes and dreams - I want to have		1, 2, 3, 5	**OSU 1:** "I'm happy…: I don't want to go hospital...I want to go to Changi (follow her father)."	

friends - I want to be part of a community - working hard to stay well - reconnecting social network			**OSU 5:** “also people I know over there e.g hospital staff and friends that I have made when attending the course…” **OSU 3**: " I want to talk more with my online friend.”

Appendix 24: University of Birmingham Ethics Approval Letter

UNIVERSITY OF BIRMINGHAM

FINANCE OFFICE

11th July 2018

Dear Prof John Rose & Dr Biza Stenfert Kroese,

Re: "Attitudes of healthcare professionals towards people with neurodevelopmental disorders and mental illness in Singapore"
Application for Ethical Review ERN_17-1730

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly bought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Further information about the University of Birmingham's ethics review process can be accessed at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/University-Ethical-Review.aspx.

If you have any queries regarding the above, please do not hesitate to contact me further.

Kind regards,

Ms Sam Waldron
Deputy Research Ethics Officer
Research Support Group
University of Birmingham
B15 2TT
Tel:
Email:

Appendix 25: Research Approval Letter from Singapore



3 Fusionopolis Link
#03-08 Nexus@one-north
Singapore 138543
Tel: 6496 6600 Fax:6486 6870
www.nhg.com.sg
RCB No. 200002150H

NHG DSRB Ref: 2018/00956

14 February 2019

Ms Lim Jan Mei
Department of
Psychology
Institute of Mental
Health

Dear Ms Lim

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL STUDY

TITLE: Attitudes of healthcare professionals towards people with

neurodevelopmental disorders and mental illness in Singapore

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in Institute of Mental Health.

The approval period is from 14 February 2019 to 13 February 2020. The NHG DSRB reference number for this study is 2018/00956. Please use this reference number for all future correspondence.

The documents reviewed are:

a) NHG DSRB Application Form: Version No. 1

b) Participant Invitation Letter: Version 1 dated 01 March 2018

c) Assessment of capacity to consent: Version 1 dated 01 March 2018

d) Participant Demographic Sheet – For healthcare professionals only: Version 1 dated 01 March 2018

e) Participant Demographic Sheet – For family carers only: Version 1 dated 01 March 2018

f) Interview Schedule For Healthcare Professionals: Version 1 dated 01 March 2018

g) Interview Schedule For Family Carers: Version 1 dated 01 March 2018

h) Interview Schedule / Activity For Discussion For Service Users: Version 1 dated 01 March 2018

i) Appendix 4 – Sample of questionnaire for 2nd phase of study

j) Simplified Informed Consent Form For Service Users: Version 1 dated 07 May 2018

k) Documentation of Capacity: Version 1 dated 01 August 2006

l) Informed Consent Form For Healthcare Professionals: Version 3 dated 09 January 2019

m) Informed Consent Form For Caregivers: Version 2 dated 11 July 2018

n) Informed Consent Form for Service Users: Version 2 dated 11 July 2018

o) Participant Information Sheet: Version 1 dated 01 March 2018

p) Assent form: Version 2 dated 27 January 2019

Continued approval is conditional upon your compliance with the following requirements:

1. Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

2. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.

3. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.

4. Please note that for studies requiring CTA/CTN/CTC, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

5. Please submit the following to the NHG DSRB:

a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. For more than minimal risk studies, all problems involving local deaths must be reported as soon as possible, but not later than 7 calendar days after first knowledge by the Investigator, regardless of the causality and expectedness of the death event, and any additional relevant information about the death should be reported within 8 calendar days of making the initial report. For no more than minimal

risk studies, only problems involving local deaths that are related or possibly related to the study must be reported as soon as possible, but not later than 7 calendar days after first knowledge by the Investigator, and any additional relevant

information about the death should be reported within 8 calendar days of making the initial report. For problems which are life threatening, it should be reported as soon as possible, but not later than 7 calendar days after first knowledge by the investigator, and any additional relevant information about the problems should be reported within 8 calendar days of making the initial report. All other problems that fulfil the UPIRTSOs reporting criteria must be reported as soon as possible but not later than 15 calendar days after first knowledge by the Investigator.

b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond 13 February 2020 until approval is renewed by the NHG DSRB.

d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.

With the enactment of the Human Biomedical Research Act, Health Products Act, Medicines Act and their subsidiary legislations, Principal Investigators are reminded to ensure that their research complies with the regulatory requirements stipulated in the applicable Acts. Contraventions under any of these Acts are criminal offences and would result in fines or imprisonment or both, subject to the nature of the offence.

Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit www.research.nhg.com.sg.

The NHG DSRB operates in accordance to the ICH GCP and all applicable laws and regulations.

Yours Sincerely

Dr Patricia Yap
Chairman
NHG Domain Specific Review Board F2
Cc: Institutional Representative, IMH
c/o Research Division, IMH
Departmental Representative of Psychology, IMH

(This is an electronic-generated letter. No signature is required.)

Appendix 26: Personal reflections (Links to Chapter 4 to 8)

This appendix details the reflections that I have developed over the course of the PhD and while carrying out the empirical studies in Singapore. Prior to starting my PhD, I worked as a clinical psychologist in Singapore's community and tertiary mainstream MH settings. At times, I encountered people with ID in my practice and felt uncertainty about how to work with them. I consulted my MH colleagues who informed me that they declined these cases and referred them to specialist MH ID services. I began to reflect that having a lack of work experience could shape the attitudes of HCPs towards this group of SUs which in turn must have an impact of their willingness to work with them.

There were minimal interactions with adults with ID during my clinical practicum training with the exception of conducting psychometric assessments with children with ND. This resulted in an inadequate knowledge of providing psychological interventions for adults with ID. I also reflected on my clinical practice and found myself working mainly with FCs on behavioural management or parent training and not offering direct one-to-one intervention to people with ID. Anecdotal conversations with my colleagues suggested that they shared similar experiences, psychological therapy is often not offered as a treatment option to people with ID and medical practitioners rely on medication as a way to control challenging behaviours. FCs of people with ID whom I had worked with shared their frustrations with me and reported burnout, negative thoughts of incompetence and feelings of self-blame that affected their relationship with their relatives.

Reflecting on my own culture, I notice that people with ID are often absent in the community. Social service programmes for people with ID place high importance on them

becoming employable so that they can contribute to the community. However, for those who are less successful in this route, the options are limited and they are neglected and/or isolated, and the public does not have much contact with them. There is a strong belief within our culture that people with ID are required to adapt and keep up with the competitive 'rat race' in order to be accepted in society. There seems to be one specific route for people with ID, to improve their lives through being employed. There is little room for them to consider alternative options or have a say about how they want to participate in the community. With my own work experiences and understanding of my culture, I decided to find out how HCPs feel about working with people with ID and MH problems and the challenges they encounter in their work.

Reflections on Chapter 4 and 5

Chapter 4 and 5 has shed light onto how adults with ID access (or do not access) specialist MH services by means of their encounters with mainstream and specialist MH professionals. Initially, I was intending to analyse the interviews of mainstream and specialist MH ID staff together as a group. However, it was beginning to emerge from the interviews that I collected that they were two distinct samples and analysing them as a whole would mean that some of their views would be curtailed. Hence, I decided to separate participants into two distinct studies that each highlight the different issues and concerns raised by both groups. Whilst the MMHPs talked more about increasing skills competency and knowledge as a way to improve the current services for people with ID, SMHPs focused on systemic and cultural factors that have an impact on service delivery. SMHPs narratives identified details about the public perception of people with ID and the stigma that they and their FCs

experience. Moreover, SMHPs focused on the need to spend time to build trusting relationships with adults with ID and their stakeholders while MMHPs focused more on the technical aspects of clinical competency, such as history taking and making an accurate diagnosis. Their views on the desirable qualities for MHPs show some differences as MMHPs prefer having the necessary skills and knowledge while SMHPs prioritise passion and having an interest in working with this population as prerequisites for working with this group.

Gaining the perspectives from MHPs provides new insight and knowledge into the current literature of disability studies related to healthcare needs in a Singapore context. I did not expect that there would be a diverse group of participants with varying work experiences and speciality who were willing to share their views and experiences. I initially considered carrying out focus group interviews as it would be interesting to observe and examine the group interactions between the participants during the interviews. However, it was difficult to arrange a suitable time and venue for MHPs to attend such a group due to their work schedules. The composition of the participants' demographics was something that I could not control for between the groups as most of the MMHPs work individually within their service whereas SMHPs work in a multidisciplinary team. Hence, the MMHPs are mostly medical staff whereas the SMHPs are a more diverse group which may contribute to the differences in the findings across both studies.

Having come from a similar culture and professional background as the MMHP, I was acutely aware of and reflected on the challenges that they faced working with this group of SUs especially in relation to stigma. Although strides have been made to address public stigma towards mental illness in Singapore, there remains a lack of public campaigns and awareness about improving the lives of people with ID, especially those with MH problems.

Having a dual diagnosis is likely to evoke significant public stigma and prejudice especially when these SUs are accessing community services, such as taking public transportation. There have been improvements in public accessibility for people with physical disabilities to promote their integration in the community but there is a lack of focus and efforts to improve their participation in the community. The culture in Singapore is primarily focus on economic productivity where people are valued based on how much they contribute to society. Hence people with ID are ostracised or kept away in residential setting when there is nobody to take care of them which can contribute to stigma and prejudices among the people in the community. There remains more to be done to address the stigma in relation to ID.

MHPs in both studies talked about the vital role of FCs during the treatment process and SMHPs described how having family support makes a significant positive impact on the care plan of the service user and the long-terms outcomes. To explore FCs' perspectives of the specialist MH ID service and how they make sense of the services provided for their relative with ID became my next aim. Moreover, the SMHPs made suggestions for future services for FCs and SUs in the community and as such, it would be useful to have both groups of voices to be heard in this research thesis so that future services can be tailored to their specific needs.

Reflections on Chapter 6

One of the challenges faced when carrying out this research was the recruitment of FCs. Initially, FCs were reluctant to participate in this study despite allied MHPs approaching them. Instead, I decided to consult with medical doctors and explained my study and I was

granted permission to approach FCs after their consultation review. This proved more successful in recruiting family members after the medical doctors provided brief explanation of the study. In order to reduce the possibility of coercion from their medical doctors, the FCs were allowed to have a minimum of 24 hours before deciding whether they wish to participate in the study.

Reflecting on my own experiences as a citizen in Singapore, I realise that it is not surprising that FCs expressed that society is not forgiving or patient towards people with ID. This was also reflected in MHPs accounts in Chapter 4 and 5. Our society has progressed rapidly within a short span of less than 100 years during which we have become one of top GDP countries in the world. It has been ingrained in citizens that they are an important workforce and must contribute to the high economic productivity. This creates difficulties for some segments of the population which are unable to keep up with the pace and thus are left behind and excluded. During the interviews, there were moments of pauses where FCs were asked to consider their family member's future, that suggest that they were not prepared to consider the possibility that their relatives could fully integrate in their community and be accepted for being the person they are.

During the course of research, I became interested in exploring the voices of SU s who received the specialist services. The interviews with FCs and MHPs showed that the voices or perspective of SUs are largely ignored or taken for granted. Reflecting from my perspective as a MMHP, I realised that it is important to ensure that the voices of the SU s are heard. It is common practice for (non-ID) hospital policy makers to seek the SU s' advice and feedback regarding evaluation of services and their level of satisfaction towards MHPs' attitude and treatment towards them. Therefore, the next study was designed to provide an

opportunity to understand more about the SUs with ID and their needs. Additionally, I considered it important to ask them about how they are treated and viewed by MHPs. This will provide a unique insight into SUs' experiences when receiving specialist services.

Reflections on Chapter 7 and 8

The studies in Chapter 7 and 8 provide similar and contrasting experiences of OSUs and ISUs. There were differences regarding the choice and autonomy they had over their lives. OSUs had more work opportunities, social interactions and support from their families whereas ISU were excluded in an institutionalised setting with few activities and interactions with the community. Despite these differences, all SUs mentioned similar desirable attributes for SMHPs, had minimal involvement in their own MH care and acquiesced with the decisions made by SMHPs and FCs.

Reflecting on my own stance as a Singapore citizen and my work experiences in a MH setting, I can see how these marginalised groups are ignored and stigmatised by the public which makes it harder for them to integrate and become part of society. Our culture places a high value on economic productivity and success which results in these marginalised groups being left behind and their needs being neglected. Keeping people with ID in an institutionalised setting without their consent and denying their involvement in their own health care is an archaic and easy way to address service gaps. The SUs in these studies have well represented views and want to be treated with respect and become a part of the community. Carrying out the interviews in the hospital wards with the ISUs made it easier for me to step into their shoes and I could identify with their concerns regarding the environment and standard of treatment. There were moments when I could hear screaming

and shouting from other patients and witnessed how ISUs mostly spent their time sitting on the floor without any activities to keep them engaged.

Initially, I had similar preconceived assumptions that it would be challenging to interact with the SUs and gain insight into their views. Surprisingly, the data collection process changed my views, as participants in both studies were able to engage and express strong views about themselves, their situation and the services. Moreover, the participants were able to evaluate positive and negatives aspects of their experiences with SMHPs, suggesting they have the ability to explore and provide their feedback about services despite their cognitive difficulties. There is an inherent bias in Singapore that is highlighted across the studies with MHPs and FCs in Chapter 4 to 6 that people with ID lack the competence to make decisions related to healthcare issues and unable to express their views. This has resulted in very limited participation in their own care and made them reluctant to speak out for fear of being treated harshly. Both studies in chapter 7 and 8 show that it is possible for people with ID to share their views with appropriate adaptations to support their communication needs. Future research should take this into consideration and involve people with ID in disability-related studies.

The findings in both studies are in line with the previous studies with SMHPs and FCs in chapters 5 and 6 on the provision of specialist MH ID service in Singapore. FCs perceived the benefits of the services as having SMHPs to prescribe medication to deal with the challenging behaviours whereas SMHPs stated that the aim of the service is to reduce the symptoms and work with all stakeholders to integrate them into the communities. SUs would like for services to help them maximise their competency so that they can find work and develop social relationships. The different groups of participants have differing views on

the impact of the specialist MH ID service. Upon further reflection, I start to wonder what influence the specialist MH ID service has on SUs level of community integration and the impact of public perception towards people with ID. I started to consider what outcome measures are used by specialist MH ID service as some of the people with ID remain in an institutionalised setting even after receiving treatment. Hence, I will explore a qualitative approach to summarise the themes across the five studies in order to understand whether the specialist MH ID service has any impact on the choice, autonomy and integration of people with ID in the community.