

Psychologists' Adherence and Carer Experiences with Best practice in Intellectual Disabilities and Co-morbid Mental Ill Health

Joyce Man

BA-Psych, Grad Dip. Science (Psychology), M. Psych (Clinical Psychology)

Centre for Emotional Health, Department of Psychology,

Faculty of Human Sciences, Macquarie University

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Dedications

To all families caring for a child with an intellectual disability, you are all warriors.

To all who dedicate themselves to improving the lives of individuals with intellectual disabilities, thank you for continuing to humble and inspire me.

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Abstract

This thesis explored Australian psychologists' perceptions of best practice when working with individuals with an intellectual disability and co-morbid mental health disorders and its alignment with carer experiences. The first study explored assessment practices, perceptions of workplace resources, training needs and barriers to evidence based practice of Australian psychologists working in intellectual disabilities via an online survey. Study two involved focus groups with psychologists working in intellectual disabilities and investigated their perceptions of best practice, adherence to practice guidelines and impact of organisational factors. The final mixed method study used online surveys and face to face/phone interviews to explore experiences of carers with an offspring with dual disabilities with mental health and disability services. This study also assessed carer mental health literacy and barriers to help seeking. Overall, findings indicate that psychologists are generally aware of best practice principles and reported clinical practices that are aligned with current international and national practice guidelines. Psychologists showed limited confidence in mental health diagnosis with individuals with an intellectual disability and expressed a need for further training in dual disabilities. Organisational and systemic factors were found to create barriers to evidence based practice implementation and practice based evidence was noted to compensate for the limited evidence based available to guide clinical practice. Carers reported varying experiences of helpfulness and satisfaction with mainstream mental health and disability services. Carers also generally showed high mental health literacy and reported few attitudinal barriers to help seeking. Carers also noted more negative than positive experiences with services received for their offspring with dual disabilities. Findings suggest there is much improvement to be made in a range of areas to improve the experience of carers with services to address mental health concerns. Findings from this thesis have implications for clinician training, organisational operations, service models of care, practice guideline implementation and practice based evidence.

Statement of candidate

I certify that the work in this thesis entitled “Psychologists’ Adherence and Carer Experiences with Best practice in Intellectual Disabilities and Co-morbid Mental Ill Health” has not previously been submitted for a degree nor submitted as part of requirements for a degree to any other university or institution other than Macquarie University.

I also certify that this thesis is an original piece of research and has been written by me. All information sources and literature used are indicated in the thesis. Any assistance received in preparation of this thesis itself has been acknowledged.

The research presented in this thesis was approved by Macquarie University Ethics Review Committee, reference number: 5201300380 on 4th July 2013, reference number: 5201400983 on 30th October, 2014 and reference number: 5201500759 on 13th October, 2015.



Joyce Man (Student ID 30651271)
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Chapter 1: Introduction

Intellectual disability is characterised by deficits in intellectual functioning accompanied by one or more areas of impairment in conceptual, social or practical adaptive functioning with an onset during the developmental period (American Psychiatric Association, 2013). It is widely documented that individuals with an intellectual disability compared with the general population exhibit higher levels of impairment in their everyday functioning (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). In fact, people with an intellectual disability are at least two to three times more likely to acquire a mental disorder compared with the general population (Bouras & Holt, 2010), yet have greater difficulty in accessing appropriate mental health care (Fletcher et al. 2009).

Dual disability is a term often used to describe people who have an intellectual disability and a concurrent mental health condition (Mohr, Phillips, Curran & Rymill, 2002). Assessing the mental health of individuals with intellectual disability is associated with a number of challenges (Costello & Bouras, 2006; Rush et al., 2004). Both intellectual disability and mental health disorders are associated with impairments in daily functioning. As a result, the presence of mental illness in individuals with intellectual disability creates additional complications in the assessment process. For instance, diagnostic overshadowing, where mental health presentations of an individual are attributed to their intellectual disability (Costello & Bouras, 2006) appears to be widespread across clinicians working with individuals with dual disabilities (Mason & Scior, 2004). For psychologists, limited training and expertise in intellectual disabilities in combination with limited evidence base in this specialist field can create barriers to accurate mental health assessments with individuals with dual disabilities. This chapter will highlight some of the common complexities associated with diagnosing mental health disorders in individuals with an intellectual disability, outline current evidence base guidelines and resources, psychology training in intellectual disabilities from a national and international perspective, service delineations and workplace factors impacting on evidence based practice adherence and carer experiences

with services. This thesis aims to understand the impact of the aforementioned challenges on psychologists' overall clinical practices in dual disabilities and in relation to mental health assessment via two phases of research. How these practices are experienced by the recipients of these services will be explored in the third and final phase of this thesis focusing on family carer experiences of disability and mental health services.

Conceptualisations of Challenging Behaviour and Mental Health Disorders

Intellectual disability is considered a neurodevelopmental disorder within current diagnostic manuals; Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychological Association, 2013) and the Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines (ICD-10) (World Health Organisation, 1992), and distinct from acquired mental disorders (Mental Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities to the World Health Organisation, 2001). Mental disorders on the other hand, are defined as 'a clinically significant behavioural or psychological syndrome or pattern that occurs in a person that is associated with present distress or disability' (American Psychological Association, 2013, p. 20). In contrast, neurodevelopmental disorders typically have an onset in the developmental period and are characterised by developmental deficits leading to 'impairments of personal, social, academic or occupational functioning' (American Psychological Association, 2013, p. 31). As a result of these deficits, some individuals with intellectual disability may present with challenging behaviours, that is, behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be seriously compromised, or behaviour likely to hinder access to and use of ordinary community facilities (Emerson et al., 1987). Typical challenging behaviours of individuals with an intellectual disability presenting for clinical

attention include physical aggression, destructiveness, self-injury, and sexual behaviours of concern (Allen & Davies, 2007).

Clinicians require experience and expertise to decipher whether an individual's presentation can be explained by their intellectual disability, a possible sign of a mental health condition or attributed to other factors. Challenging behaviours and mental health disorders have a number of possible relationships and are not necessarily mutually exclusive presentations. Costello and Bouras, (2006) describe three possible ways in which challenging behaviour and mental health disorders can be related. One such relationship involves challenging behaviour and mental health problems sharing the same biological basis. Challenging behaviour may also be a reflection of how mental health symptomatology is expressed. Thirdly, challenging behaviour may occur in an attempt to terminate aversive events during periods of mental illness, or mental health conditions may act as an establishing operation for challenging behaviour. For example, an individual may engage in self-injurious behaviours via head banging in an attempt to drown out self derogatory auditory hallucinations associated with psychosis.

Despite these possibilities, individuals with dual disabilities often have their presentations dichotomised by clinicians as either due to a psychiatric disorder or a challenging behaviour (Mohr, Curran, Coutts, & Dennis, 2002). In doing so, clinicians neglect an array of possible relationships between psychiatric disorders and challenging behaviours. The heterogeneous nature of intellectual disability can also make it difficult to disentangle the multiple possible causes of psychopathology in intellectual disability (Pickard & Akinsola, 2010). This has direct implications for service provision and the service taking primary responsibility and case coordination for the individual (Mohr et al., 2002). Despite the ongoing practice of dichotomising challenging behaviour, no conceptual basis for this dichotomy exists (Pickard & Akinsola, 2010).

Diagnostic Overshadowing within Mental Health Assessments

In relation to mental health assessment, diagnostic overshadowing is a practice which can compromise the specificity and sensitivity of mental health diagnoses. Some factors contributing to diagnostic overshadowing include: psychosocial masking whereby diminished social skills and life experiences may lead to masking of internalising or less overt symptomatology; and cognitive disintegration where people with an intellectual disability' lower thresholds for stress and anxiety may be misattributed to their lower cognitive functioning (Costello & Bouras, 2006). Given its impact on psychopathology identification, the prevalence of diagnostic overshadowing has been explicitly examined with clinicians (Mason & Scior, 2004) and direct support staff (Costello, Bouras, & Davis, 2007).

In a study using clinical case vignettes of people with and without intellectual disabilities, it was found that clinicians were more likely to recognise mental health symptoms in those cases with normal intellectual functioning compared to those with an intellectual disability (Mason & Scior, 2004). Compared with clinical psychologists, psychiatrists also exhibited more rates of diagnostic overshadowing (Mason & Scior, 2004). In another study, Costello and colleagues (2007) found inaccuracies in care staff in identifying mental health concerns in individuals with an intellectual disability that they supported. Prior to mental health training, one third of cases of individuals with an intellectual disability with mental health concerns were identified as free from mental health concerns by care staff (Costello et al., 2007).

Given the prevalence of diagnostic overshadowing and other highlighted challenges associated with mental health diagnosis, there is a need for evidence based guidelines to provide greater clarity around the diagnostic process for this specialist population. Existing research has neglected to investigate how such diagnostic challenges specifically impact on

clinicians who work with individuals with dual disabilities. In response to this, phase one of the thesis will investigate current views and clinical practices of psychologists working in dual disabilities given their role in meeting the mental health needs of individuals with an intellectual disability.

Evidence Based Practice in Dual Disabilities

Research literature on dual disabilities is continuing to emerge. Some current focuses include exploration of behavioural equivalents of specific mental health disorders (Rojahn & Meier, 2009), the relationship between challenging behaviour and psychiatric disorders (e.g. Felce, Kerr, & Hastings, 2009) and the development of specialised assessment tools and methodology (e.g., Mohr et al., 2005; Singh et al., 2006). At present, two main diagnostic manuals are available to assist with the diagnostic process for clinicians working with individuals with intellectual disability. The Diagnostic Manual-Intellectual Disability 2 (DM-ID 2) (Fletcher, Fletcher, Barnhill & Cooper, 2016) was developed based on the DSM-5 criteria (American Psychological Association, 2013). The Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) was based on available evidence using ICD-10 criteria (World Health Organisation, 1993). Despite these advances, it is beyond the scope of diagnostic manuals to detail special considerations and complexities of mental health assessment for people with dual disabilities. A more comprehensive framework is needed to guide clinicians on how such resources are to be integrated within a mental health assessment.

Given the complexities associated with mental health assessment for individuals with an intellectual disability, practice guidelines exist to provide best practice recommendations to clinicians. Currently, a number of guidelines on mental health assessment for people with an intellectual disability have been developed in the United Kingdom (e.g. National Institute for Health and Clinical Excellence, 2016). Also, in Australia, a guideline on working with

people with dual disabilities was launched to guide mainstream mental health service delivery (Department of Developmental Disability Neuropsychiatry (3DN), 2014). Despite these initiatives, no consensus exists in relation to the gold standard for mental health assessment for this specialist population. Furthermore, no research has focused on the application of specific practice guidelines by clinicians in the dual disability field. Given the lack of international consensus on best practice, how psychologists conceptualise and implement mental health assessment when working with individuals with an intellectual disability has yet to be well understood. Knowledge of whether such practices are in line with currently available practice guidelines would assist in gauging current benchmarks of clinical practice to inform future training and support to clinicians. Accordingly, phase one of the thesis will also explore current mental health assessment practices of psychologists working in intellectual disabilities given current limitations with evidence based guidelines. A more detailed view of best practice and views on available practice guidelines will also be explored in phase two of this program of research with psychologists who work with individuals with dual disabilities.

Psychology Academic Training and Workplace Training in Intellectual Disabilities

Psychologists play a key role in the delivery of mental health and challenging behaviour services for individuals with an intellectual disability, particularly in the area of mental health assessment. Currently in Australia, the most common psychology registration pathways are via the 4+2 pathway (involving four years of undergraduate training in psychology followed by two years of supervised internship); or the masters pathway (involving four years of undergraduate training followed by two years of specialist masters training) which are being subject to review (Littlefield, 2016). Neither pathway consists of mandatory training in intellectual disabilities. As a result, didactic training in intellectual disabilities is more commonly experienced via placements within postgraduate psychology

programs or accumulated via work experience in the intellectual disability field. Similarly in the United States and Canada, training in intellectual disabilities is not a mandatory component of psychology academic training (American Psychological Association, 2009; Canadian Psychological Association, 2002). On the contrary, in the UK, training in intellectual disabilities is built into doctorate professional psychology training (British Psychological Society, 2005). In the UK, a work placement in an intellectual disability setting comprises one out of four compulsory work placements. As a result, postgraduate psychology graduates develop a thorough foundation of training in dual disabilities and are more likely to show competence in meeting the mental health needs of this population. Given this, it is possible that psychologists without such experience or post-graduate training in intellectual disabilities lack specialised knowledge and skills to work with this specialist population.

Beyond formal training within postgraduate psychology degrees, continued professional development in mental health assessment and intervention are also important in building competency in this specialist area. This is especially important for clinicians working in the intellectual disability field where no prior formal training has been received. With the integration of individuals with an intellectual disability into mainstream health services in Australia, this has left staff feeling undertrained and inadequate in meeting the needs of this specialist population (e.g. Rose et al., 2007). In Australian psychiatry, initiatives have been made to introduce competency training in intellectual disabilities to psychiatrists (Johnson et al., 2013). A one year competency based training for intellectual disabilities has been adapted from a UK 3 year program for the purposes of increasing expertise in intellectual disabilities within psychiatric training. To date, no similar initiatives exist with psychology training in Australia.

With regards to other training initiatives, Australian researchers investigated the impact of an interagency training between the public health and disability sectors in a range of professions (Mohr et al., 2002). Pre and post training measures indicated increased confidence, knowledge in dual disabilities and a commitment towards further interagency collaboration and changing of work practices. A review by Rose and colleagues (2012) focusing on mental health training provided to staff working with individuals with an intellectual disability found that training can effectively increase skills, knowledge and attitudes. Given the lack of mandated training in intellectual disabilities within psychology undergraduate and postgraduate academic training in Australia, how this impacts on psychologists' sense of competency and confidence in this specialist field is unknown. This knowledge would contribute to our understanding of specialist training needs required in order to strengthen competency in this profession with the dual disability population. Accordingly, this will be specifically explored via quantitative (phase one) and qualitative studies (phase two) regarding the clinical practices and views on mental health assessment with psychologists in dual disabilities in this current program of research.

Workplace Barriers and Facilitators to Best Practice Implementation

Given the heterogeneous nature of mental health service delivery to individuals with an intellectual disability, service models and standards of practice will inevitably vary as a consequence. In the mainstream literature, organisational factors have been found to significantly impact on uptake of evidence based practices. In particular, Gallow and Barlow (2012) found a lack of organisational and systemic supports were hindrances to evidence based practice uptake in mainstream psychology. Estabrooks (2003) highlighted the need for a supportive organisational climate in order to facilitate evidence based practice. For instance, a supportive organisational climate for nurses consists of managerial support, facilitation, and a culture that is receptive to change (Gerrish & Clayton, 2004). In the field

of intellectual disabilities, it is unclear how organisational factors impact on clinician views on best practice and the implementation of practice guidelines. Services for individuals with dual disabilities typically involve a systemic approach which cuts across health, disability, education, occupational and leisure sectors. Given that systemic factors are likely to play an important role in service delivery, it is important to examine whether current services are in keeping with best practice standards. In furthering our understanding of the impact of workplace factors on best practice, this will assist in identifying barriers and facilitators in order to improve evidence based practice implementation. This will be explicitly explored in phase two of the thesis via focus groups with psychologists working in the intellectual disability field.

Service Delineations and Access for Adults with Dual Disabilities

Currently in Australia, principles of normalisation (Foreman & Arthur-Kelly, (2008) have resulted in the de-institutionalisation of people with an intellectual disability moving from residential institutions into the community. This movement has had major ramifications for service provision. In New South Wales (NSW), disability services are governed by the Disability Inclusion Act 2014 which emphasise accessibility of mainstream services and facilities and community inclusion for people with disabilities (New South Wales Consolidated Acts, 2014). In Australia, mainstream mental health providers and disability services operate as separate entities, with limited communication between providers resulting in unfamiliarity with one another's service provision (Mohr et al., 2002). With the reintegration of people with an intellectual disability into mainstream community services, the provision of mental health services for individuals with an intellectual disability revert to mainstream mental health services via public inpatient and outpatient hospital services, community centres, GPs and private psychiatrists. In NSW, public mental health services for people with dual disabilities are generally provided by local hospitals in

inpatient and outpatient settings and community health centres. Since November 2006, subsidised private psychology services have also been available via the Better Access to Mental Health Care Initiative (Australian Psychological Society, 2007). The primary social and welfare needs of people with an intellectual disability on the other hand are typically serviced by the government disability services and non-government organisations. Difficulties arise in service provision and coordination for people with dual disabilities whose needs typically span across both of the disability and health sectors.

In the international literature there appears to be a general consensus among mental health clinicians in mainstream settings that specialist mental health services for people with an intellectual disability may better serve the mental health needs for this population (e.g. Trollor, 2014). Moreover, integration of people with an intellectual disability into mainstream health services has resulted in staff feeling undertrained in meeting the needs of people with an intellectual disability (Chaplin, 2004; Rose et al., 2007). In Australia, public mental health services often limit service provision to those with serious psychotic and mood disorders which often leads to restricted access of mental health services for people with an intellectual disability (Torr, 2013). When presented to a public mental health service, it has been reported that psychiatric triage may refuse service to individuals with an intellectual disability without a formal mental health assessment (d'Abrera, 2008; Torr, 2013). Based on data from a Western Australia data linkage study, it has been found that a majority of people with dual disability accessed disability services prior to accessing mental health services (Torr, 2013). Furthermore, people with dual disabilities were more likely to experience inpatient admission, more frequent admissions, longer stays and to self-harm or attempt suicide compared to people without an intellectual disability (Torr, 2013). In Canada, emergency department staff reported feeling ill-equipped to meet the needs of individuals with an intellectual disability (Lunsky, Gracey, & Gelfand, 2008), although there is a growing recognition for specialist services (Lunsky et al., 2010). These findings suggest that

individuals with an intellectual disability have additional complexity in their support needs that are currently not well met in mainstream services. The support needs of an individual should be accessed in context of the interaction with their environment (Arnold, Riches & Stancliffe, 2011) and in the case of an individual accessing a mainstream mental health service, whether additional supports are required to enable the individual to receive an equitable service should be considered.

In NSW, Australia, the establishment of The Memorandum of Understanding (MOU) between Health and Ageing, Disability and Home Care and the chair in intellectual disability mental health have made attempts to bridge the gap between public health and disability services (Johnson, Bowden, Coyne, & Trollor, 2013). The MOU was developed in recognition that individuals with dual disabilities have specialist clinical needs.

Furthermore, there is growing recognition that for this population, disability and mental health services need to work collaboratively in order to have their needs effectively met. Several initiatives exist in NSW in an attempt to provide specialist dual disability services which include the specialist intellectual disability clinics in Kogarah Developmental and Assessment Service, and tertiary intellectual disability neuropsychiatry service at Prince of Wales Hospital, Randwick. Several specialist health services also exist for adults with an intellectual disability which include the Concord Specialist Unit at Concord Hospital and NSW Developmental Disability Unit and the Northern Intellectual Disability Health Service. Despite these initiatives, specialist services are often tertiary in nature and are few and far between. Access and availability of such services can also be dependent on location with certain states in Australia and urban areas holding an advantage over rural areas.

In the UK, there is a growing trend towards specialist intellectual disability and mental health services for individuals given mainstream services may not always adequately meet the needs of individuals with an intellectual disability (Brown, MacArthur,

McKechanie, Hayes, & Fletcher, 2010; Chaplin, O'Hara & Holt, 2009). Currently in the UK, individuals with profound or severe intellectual disabilities are seen in specialist services while individuals with a mild to moderate intellectual disability typically access intellectual disability services or mainstream mental health services, or a combination of both (O'Brien and Rose, 2010). However, there have been mixed findings regarding the efficacy of specialist services in meeting the complex mental health needs of individuals with an intellectual disability and their families. An earlier UK review of mainstream and specialist dual disability services also found no conclusive evidence to favour the use of general or specialist psychiatric services (Chaplin, 2004). Moreover, Hemmings and colleagues (2014) more recently suggested that specialist training within mainstream services may better serve individuals with dual disabilities. They noted little support for separate intensive specialist services for individuals with an intellectual disability. In Canada and Australia, mainstream mental health services are largely viewed as generic and lacking in specialist expertise to meet the needs of individuals with dual disabilities and their families (e.g., Bennett, 2014; Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014; Weiss, Lunskey, Gracey, Canrinus & Morris, 2009). Furthermore in Asia, a cross sectional study across nine Asian countries found that only half the countries surveyed adopt normalisation principles with many countries lacking clear social and healthcare policy and up to date mental health legislation to manage behavioural and psychiatric problems in people with an intellectual disability (Kwok & Chui, 2008). All services also reported inadequacies in meeting the mental health needs of adults with an intellectual disability (Kwok & Chui, 2008).

To date, limited studies exist which examine Australian mainstream services in their ability to provide mental health services to individuals with an intellectual disability. Given the varied international landscape of disability and mental health service models, it would be important to explore whether Australian mainstream services are adequate in meeting the

mental health needs of individuals with dual disabilities and their compliance with international best practice standards. This will be examined in the second phase of the thesis, which is based on focus groups with psychologists working in disability settings with their views on best practice in dual disabilities.

Carer Experiences with Mental Health Services

Carers play a pivotal role in the lives of individuals with an intellectual disability. Referrals to mental health services are largely initiated by carers who serve as advocates, informants and support persons for individuals with an intellectual disability. Given the instrumental role of carers in seeking services for their offspring with an intellectual disability, research has investigated factors impacting on help seeking behaviour. In particular, a Canadian study involving parents of youth and adults with an intellectual disability examined barriers to help seeking using a help seeking measure (Weiss & Lunsky, 2010). A number of factors were found to impact on help seeking such as a lack of trust and negative previous experiences with professionals, not knowing where to find help, and fear of raised problems be dismissed (Weiss & Lunsky, 2010). Beyond this, no published studies exist which formally examine help seeking attitudes and behaviours of carers in the intellectual disability field.

In order to ensure services are appropriate to the needs of this specialist population, the experience of carers who seek services for their child with an intellectual disability also require investigation given their instrumental roles in the lives of these individuals. Existing literature on carer perspectives have been largely sought with in-patient psychiatric services (e.g., Donner, Mutter, & Scior, 2010; Chinn, Hall, Ali, Hassell, & Patkas, 2011; Iacono et al, 2014), and emergency services (e.g., Lunsky et al, 2011; Weiss et al., 2009), with a small number of studies evaluating specialist services (e.g. Maitland, Tsakanikos & Holt, 2006). A review of the literature on hospital experiences of carers highlight a number of concerns

(Iacono et al., 2014). These include an over representation of individuals with an intellectual disability in emergency services, longer hospital stays, institutionalised discrimination, safety risks, incorrect medication prescription and not having basic self care needs met in acute inpatient units (Iacono et al., 2014). These findings highlight current inadequacies of carer experiences with mental health services for individuals with an intellectual disability and barriers to help seeking for carers.

In relation to community services for individuals with an intellectual disability, a study examining the efficacy of community outpatient programmes for people with dual disabilities (Hackerman, Schmidt & Dyson, 2006), and telephone consultations in a community intellectual disability unit (Bains, Bonell & Speight, 2010) have both reported positive outcomes. A UK study by Hemmings, Underwood and Bouras (2009) compared the views of adult service users with an intellectual disability, carers and professionals and found similar views in relation to what was considered essential to a community mental health service. Carers highlighted the need for prompt treatment and for readily accessible information (Hemmings et al., 2009). A review of studies on community services by Hemmings (2008) for people with dual disabilities highlights the paucity of research in this area and limited studies examining carer experiences. Given these gaps in the literature, research into carer experiences with a range of services accessed by their child (including adult offspring) with an intellectual disability with an intellectual disability is needed. This will assist in gauging a more holistic view of whether these services align with family carer expectations and considered helpful in meeting their specific mental health needs. This will be addressed in the third and final phase of this thesis with carers of individuals with an intellectual disability with an intellectual disability in terms of their experiences with services.

Mental Health Literacy and Help Seeking of Carers

Mental health literacy involves the identification of mental health problems and knowledge of where to seek help (Jorm et al., 1997). Given the complex presentation of individuals with co-morbid intellectual disability and mental health concerns (Costello & Bouras, 2006), mental health literacy is also an important area that is not well established. As previously discussed, mental health assessment of individuals with an intellectual disability comes with special considerations. Given carers are often the gatekeepers to service access for their child or adult offspring with an intellectual disability, being informed of their mental health literacy will improve our understanding of potential barriers to service access. Carer and support staff attributions of presenting problems of individuals with an intellectual disability relate closely to mental health literacy. In a UK study with group home staff, Hastings (1997) investigated support staff's attributions of the cause of the challenging behaviour presentations of their clients with an intellectual disability. Hastings (1997) found that support staff lacked accuracy in identifying the causes of challenging behaviour of their clients, and which impacted on staff's ability to make appropriate referrals for support. Furthermore, only those behaviours causing difficulties for staff were referred for services (Hastings, 1997). A study by Costello and colleagues (2007) found significant deficits in awareness and identification of mental health problems in adults with an intellectual disability in residential support staff prior to receiving mental health training. Following training, staff showed significant improvements in their ability to accurately identify mental health concerns in clients with an intellectual disability. Taken together, these findings suggest paid/professional carers may have poor mental health literacy which may hinder individuals with an intellectual disability accessing appropriate mental health services.

There appears to be a paucity of research into the mental health literacy of family members caring for an individual with an intellectual disability. In the mainstream literature, carer mental literacy has been examined with carers of foster children (Bonfield, Collins & Guishard-Pine & Langdon, 2009) and those with a child with autism (Koyama et al., 2009; Shyu, Tsai & Tsai, 2010). Given the complex presentations of individuals with dual disabilities, it is not clear whether carers are able to recognise mental health concerns in their child with an intellectual disability. Research into the mental health literacy of family carers would assist to improve the likelihood of individuals with dual disabilities being supported to access appropriate mental health care.

In summary, in response to research gaps in implementation of evidence based practice in the field of intellectual disabilities and co-morbid mental health concerns and training needs of psychologists, phase one of the thesis will address clinical practices and views of psychologists regarding their work with individuals with dual disabilities. To address the paucity of research regarding the impact of organisational factors on evidence based practice implementation in the intellectual disability field, this will be the focus of phase two. Finally, gaps in the literature regarding carer experiences with services beyond mainstream mental health services including barriers impacting on help seeking and carer mental health literacy will be addressed in phase three of the thesis.

Thesis Aims and Structure

The aims of this thesis are to address some of the gaps in the research literature pertaining to psychologists' clinical practices when working with individuals with an intellectual disability and co-morbid mental health concerns. More specifically, the objective was to investigate psychology competency in dual disabilities (phases 1 and 2) and whether this aligns with carer experiences (phase 3). Three separate studies were conducted to explore these aims. The aim of study one was to explore Australian psychologists' views

regarding their work with individuals with dual disabilities and their clinical practices in relation to mental health assessment (Chapters 2 and 3). Chapter two aims to provide an overview of psychology clinical practices and views on clinical competence, work place supports and training needs in dual disabilities and whether there are differences between work settings. Chapter three investigates reported mental health assessment practices of psychologists working with adults with an intellectual disability and barriers to evidence based practice implementation.

On the basis of the outcomes from Phase one, the objective of the second study was to conduct a more detailed investigation of psychologists' views on best practice and reported clinical practices (Chapters 4 and 5). Chapter four aimed to investigate whether the reported clinical practices of Australian psychologists aligned with national and international best practice standards and ways in which psychologists adapted to the limited evidence base for dual disabilities. Chapter five investigated Australian psychologists' adherence to practice guidelines as well as factors which facilitate and hinder evidence based practice implementation.

Having gained a better picture of clinician practices in dual disabilities, the aim of the third and final phase of this program of research was to explore the experiences of services from a carer perspective with disability and mental health services via a mixed method study (Chapters 6 and 7). The focus of chapter six was on family carers' perspectives on the helpfulness and satisfaction with mental health and/or disability professional services, carer mental health literacy and barriers to help seeking for their child/adult offspring with an intellectual disability. Chapter seven aimed to explore carers' experiences with mainstream services and their suggestions on ways to improve existing services. The final chapter of this thesis (Chapter 8) provided a general discussion of this program of research in which the

findings across the three phases were collectively considered and the implications for clinical practice and future research directions presented.

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Chapter 2: PHASE 1 PAPER 1

Clinical Competencies and Training Needs of Psychologists Working with Adults with Intellectual Disabilities and Co-morbid Mental Health Concerns

Joyce Man¹, Maria Kangas¹, Julian Trollor² and Naomi Sweller³¹

¹ Centre for Emotional Health, Department of Psychology, Macquarie University

² Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Australia, UNSW, Sydney NSW 2052

³ Department of Psychology, Faculty of Human Sciences, Macquarie University

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¹ This is to confirm Joyce Man is the first author and has completed all field work, data analysis and the first full draft of this paper.

Abstract

Objectives: Psychologists play a pivotal role in meeting the mental health needs of people with an intellectual disability. The aim of the current study was to investigate the perceptions of Australian psychologists who work with adults with an intellectual disability and mental ill health regarding their clinical competencies, workplace supports and training needs.

Method: One hundred and nine psychologists in Australia completed a self-report online survey exploring clinical attitudes and practices when working with adults with an intellectual disability and mental ill health. Provisional, generalist and clinical psychologists from a range of disability and non-disability work settings were recruited.

Results: Findings revealed provisional, generalist and clinical psychologists reported no significant differences in levels of agreement on self-perceived clinical competencies in conducting mental health assessments. Psychologists in private practice and in non-government organisations reported more adequate workplace resources to support mental health assessments for people with an intellectual disability than did psychologists in government settings. Psychologists across work settings expressed similar views in self-perceived clinical competencies and workplace training supports. The majority of psychologists reported limited formal academic training in intellectual disabilities, and expressed a need for continual and specialised training in mental health and intellectual disabilities.

Conclusions: Implications for further training in mental health and intellectual disabilities highlight the need to cater to the specific needs of psychologists in the field.

Keywords: Assessment, competencies, disability, health, intellectual, mental

Key points

- Approximately half of the psychologists working in ID consider themselves specialists in mental health and ID.
- Psychologists in government disability, non-government and private practice settings reported similar views in clinical competencies in mental health assessment for people with ID and workplace training supports.
- Psychologists report limited formal academic training in ID and a need for continual and specialist training in mental health and ID.

Introduction

In Australia, 1% of the population are estimated to have an intellectual disability (ID) (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Studies report prevalence rates of psychological disorders in people with ID range from 16%, (Cooper, Smiley, Morrison, Williamson, & Allan, 2007) to 54% (Gustafsson & Sonnander, 2004) which is much higher than the general population (Cooper et al., 2007). It is therefore imperative that mental health professionals catering to the needs of people with ID are available and accessible. Psychologists are one profession considered an essential part of mental health service provision for individuals with ID; hence it is important to examine their clinical competencies and training needs given the paucity of research in this field.

Currently, psychological services for people with ID are provided in a variety of settings including local and community mental health settings, government and non-government disability services. Since November 2006, the Better Access to Mental Health Care Initiative in Australia (Australian Psychological Society, 2007) has increased accessibility to private psychology services. Given the heterogeneous nature of psychological services for people with ID, the ability to provide a timely mental health assessment based on best practice guidelines for a person with ID may be impacted by the work setting of psychologists. For instance, psychologists from public mental health settings and disability services vary considerably in the nature of their contact with people with ID, the length of time available for psychological assessment, the assessment methods employed, and the training and experience in mental health and ID (Munden & Perry, 2002). Psychologists in public mental health settings are more inclined to provide acute mental health triage, assessment and short term individual and group interventions to people without ID. Psychologists working in these settings may hold variable experience in working with people with ID. Psychologists working in disability services primarily provide behavioural

assessment and intervention to people with ID. These psychologists may also provide mental health assessment and intervention depending on their training and qualifications.

Psychologists providing mental health care to people with ID have variable professional qualifications. In particular, clinical psychologists and generalist psychologists differ in their professional clinical training. Notably, clinical psychologists in Australia undergo training in the accredited Masters of Clinical Psychology programs, which emphasise a scientist-practitioner model incorporating in-depth training in assessment, diagnosis and treatment of mental disorders (Australian Psychological Society, 2006). For provisional psychologists undergoing registration through the Australian Health Practitioner Regulation Agency (four years of undergraduate psychology study plus a further two years of a supervision program before meeting the requirements as a generalist psychologist), limited guidance exists on integrating the scientist-practitioner model into clinical practice (Psychology Board of Australia, 2013). On this basis, it would be expected that clinical psychologists would exhibit greater confidence in mental health assessments of people with ID and co-morbid mental ill health in comparison with generalist psychologists; although this proposition has yet to be empirically substantiated.

In Australia, the study of ID generally forms a small component of the overall curriculum of postgraduate coursework training in psychology. Specialisation in the area of ID is typically established either via disability placement settings during postgraduate training which are often scarce, or post-graduation, via accumulation of clinical contact and experience. Similarly in the United States, few graduate psychology training offer training in disabilities (Razza, Dayan, Tomasulo, & Ballan, 2014) while Canadian students in graduate psychology training courses report similar difficulty in obtaining adequate didactic and experiential opportunities in ID (Weiss, Lunskey & Morin, 2010). In comparison, doctoral students in clinical psychology in the United Kingdom are required to complete a 6-

month placement in a developmental disability community team (Scior et al., 2012).

Worldwide, there is limited research which examines clinical competencies of psychologists in the area of ID. It is therefore timely to investigate whether psychologists in this field report sufficient training in the assessment, diagnosis and treatment of people with ID with mental health disorders given the limited formal training opportunities available.

Psychiatry research in comparison has evaluated perceived clinical competencies of psychiatrists working with people with ID. Specifically, Australian psychiatrists have been found to report receiving inadequate training to address the mental health needs of people with ID (Edwards, Lennox & White, 2007). Psychiatrists surveyed reported greater competency to identify and treat mental health symptomatology than to diagnose mental health disorders per se (Edwards et al., 2007; Lennox & Chaplin, 1996). On the basis of these findings, the need for specialist training of psychiatrists in ID was highlighted. In response, a fellowship training programme for psychiatric registrars has been offered in NSW, Australia (Johnson, Bowden, Coyne, & Trollor, 2013). An online training module on dual disabilities was also launched offering free training in ID and mental health to all mental health professionals including psychologists in Australia (Department of Developmental Disability Neuropsychiatry, 2013). Despite these advances, specialist training for psychologists in ID is not currently widely available in Australia. In comparison in the United States and United Kingdom, national organisations such as The National Association for the Dually Diagnosed and Estia Centre respectively provide further professional training to clinicians on improving mental health provision for people with ID.

In Australia, the National Disability Insurance Scheme (NDIS) is a new insurance based model of service offering individualised services to individuals with permanent and significant disabilities (National Disability Insurance Scheme, 2014). Given the move towards non-government and private sectors as primary providers of disability services,

examining perceived competencies of psychologists in these settings has utility in identifying gaps in training to promote clinical competencies. As mainstream mental health services are not funded under NDIS, it is foreseen that psychologists providing disability services will play a larger role in the provision of mental health services to people with ID and it is therefore timely to examine current skills and training requirements of psychologists.

Present Study

Given the paucity of studies examining the clinical competencies and training needs of psychologists working with people with ID, the primary aim of this study was to examine psychologists' self-reported clinical competencies and perceptions on adequacy of workplace supports when working with adults with ID and co-morbid mental disorders. Differences between psychologists across work settings and the professional roles of provisional, generalist and clinical psychologists were explored. It was hypothesised that due to differences in clinical training in psychology within Australia, clinical psychologists would report greater self-perceived clinical competencies compared to generalist psychologists. The second aim was to explore specialist training experiences and identified needs in working with people with ID. It was predicted that psychologists in general would report a lack of further specialised training in working with this population, and this would apply equally across different work settings and professional qualifications.

Method

Participant Characteristics

A sample of one hundred and nine registered and provisionally registered Australian psychologists (91 females, 18 males) who work with adults with ID took part in an online survey. All participants completed a minimum of 80% of survey questions, with 17%

providing partial responses. Psychologists were recruited from a range of disability and non-disability work settings. The demographic profile of participating psychologists is summarised in Table 1. Psychologists reported extensive clinical experience, ($M = 10.55$ years, $SD = 9.31$) ranging from provisional registration to 37 years. The length of stay in current work role also varied ($M = 6.45$ years, $SD = 6$), ranging from 0 to 35 years. Years of experience working with people with ID was similarly extensive ($M = 11.98$ years, $SD = 9.32$), ranging from provisional registration to 42 years. On average, 51% ($SD = 34.37$) of psychologists' caseloads were individuals with ID and mental ill health (range 0-100%).

Measures

Following a literature review and identification of existing gaps in knowledge, a self-report survey was developed exploring clinical attitudes and practices working with mental health issues in adults with ID. The survey included demographic information, academic and professional experience in ID, and the nature of the clinical contact with people with ID, and questions gauging level of agreement with 25 statements about the training, mental health care of adults with dual disabilities, prevalence of mental health concerns in adults with ID and assessment and diagnosis. For the latter, participants were asked to rate the extent to which they agreed or disagreed with each statement on a 5-point scale (ranging from strongly agree to strongly disagree). A list of common terms with corresponding definitions was provided to familiarise participants with the terminology and ensure the same definitions were used with reference to the statements. Dual disability referred to 'individuals diagnosed with both an intellectual disability and a mental health disorders'. Where relevant, the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR) criteria (American Psychiatric Association, 2000) were used to define key terms such as mental disorders and ID given the delays in integrating DSM-5 into clinical practice at the time the study was conducted (2014).

Table 1

Percentages of Demographic Characteristics

Groups	<i>n</i>	Percentage of total sample
State [Total sample]	109	100
NSW	65	59.6
ACT	4	3.7
Victoria	8	7.3
Queensland	6	5.5
Northern Territories	0	0
South Australia	6	5.5
Western Australia	10	9.2
Tasmania	12	11.0
Work setting [Total Sample]	109	100
Government disability	62	56.9
Non-government organisation	18	16.5
Private practice	22	20.2
Public health and community health setting	4	3.7
Specialist dual disability service	2	1.8
Other	7	10.1
Qualification [Total Sample]	109	100
Bachelors	57	52.3
Masters	42	38.5
Other higher qualification	10	9.2
Professional role [Total Sample]	109	100
Provisional psychologist	8	7.3
Generalist psychologist	71	65.1
Clinical Psychologist	16	14.7
Other	14	12.8

Note. Two participants reported working across two states; NSW and ACT. Some participants worked in more than one setting, hence % > 100. Rounding errors may result in total sample % ≠100.

The survey also included open-ended questions which asked about perceived training needs of psychologists working with people with ID and suggestions on how training needs could be best met. See appendix A page 55 for full survey.

Following institutional ethics approval, the questionnaire developed for the purposes of this study was piloted with three psychologists (a generalist, provisional and clinical psychologist) working with people with ID. Following feedback, the questionnaire was revised to improve relevancy of the questions to a range of psychologists. The final version was comprised of three sections, of which sections one and two are the focus of the current study. Section one included demographic items, and section two consisted of 25 statements and two open ended items on training. Section three of the survey completed by clinicians who conduct mental health assessments in their current role was excluded from this study.

Procedure

Following review of the questionnaire items and formatting, recruitment for the final online survey occurred by disseminating invitations through a variety of professional networks Australia wide including the Association of Psychologists in Developmental Disability Services (PsychDD), Medicare local networks, Australasian Society for Intellectual Disability (ASID), and the Australian Psychological Society (APS) which included the People with Intellectual and/or Developmental Disability and Psychology interest group. The online survey was developed and disseminated using Qualtrics.

Provisional and fully registered psychologists in Australia who work with adults (over 18 years of age) with ID in their clinical role were recruited. Those working exclusively with children with ID were excluded from the study.

Data Analysis

Descriptive statistics, parametric and non-parametric independent sample *t*-tests and chi-square analyses were used to initially test whether differences emerged between psychologists according to professional roles: provisional, generalist and clinical psychologists, and across work settings. Demographic variables found to significantly differ ($p < .05$) between professional roles and work settings were used as covariate variables in analyses related to specific hypotheses. One-way analyses of variance (ANOVAs) were conducted to examine psychologists' self-reported clinical competencies and perceptions in relation to workplace supports when working with adults with ID and mental ill health (aim one). Four items from the survey were used to examine aim one between professional roles (See Table 2, items 5-8) and two items were used to examine perceived adequacy of resources between workplace settings (See Table 2, items 1 and 8). Ten items from the survey were also used to compare psychologists between work settings (See Table 2, items 1-10). For these post-hoc analyses, alpha was set at a more conservative level, $p = .01$ due to the multiple comparisons conducted.

Open-ended questions were used to evaluate the second aim pertaining to perceived training needs of psychologists working with people with ID. Qualitative responses were analysed using thematic analysis and prioritised according to frequency of emerging themes by the first author. The themes generated were then reviewed by the second author for relevancy and consistency. Inter-rater reliability of 20% of qualitative responses was established with an independent external rater with clinical psychology qualifications (Mean Cohen's Kappa = 0.78, range 0 to 1).

Table 2

Significant values for Statement Comparisons Between Work Settings and Professional roles

Statements used in Work Setting Comparisons	<i>F</i>	<i>p</i>	partial η^2
1. Psychologists <i>in my current work setting</i> receive sufficient on the job training to manage people with <i>dual disabilities</i>	1.54	.220	.036
2. Continual training in dual disability is supported and/or encouraged in my current workplace	1.35	.264	.032
3. <i>Fourth year trained registered psychologists in mainstream mental health services</i> are qualified and skilled in assessing and diagnosing mental health disorders in adults with intellectual disability	.841	.435	.020
4. <i>Fourth year trained registered psychologists in disability services</i> are qualified and skilled in assessing and diagnosing mental health disorders in adults with intellectual disability	1.38	.256	.033
5. I consider myself a specialist in mental health and intellectual disability in my current clinical role	.92	.404	.022
6. I would feel more confident identifying <i>mental health symptoms</i> in adults with an intellectual disability as compared to making a <i>formal diagnosis of a mental health disorder</i>	1.00	.374	.024
7. I have the <i>adequate skills and training</i> to assess and diagnose mental health disorders in adults with an intellectual disability	2.21	.116	.051
8. I have <i>adequate resources</i> in my current workplace to facilitate assessment and diagnosis of mental health disorders in adults with an intellectual disability	6.72	.002	.139
Statements used in Work Setting Comparisons	<i>F</i>	<i>p</i>	partial η^2
9. Disability services can adequately address mental health concerns of adults with dual disabilities	5.30	.007	.113
10. Mainstream mental health services can adequately address mental health concerns of adults with dual disabilities	.22	.802	.005

Statements used in comparisons between Professional Roles	<i>F</i>	<i>p</i>	partial η^2
5. I consider myself a specialist in mental health and intellectual disability in my current clinical role	.31	.048	.070
6. I would feel more confident identifying <i>mental health symptoms</i> in adults with an intellectual disability as compared to making a <i>formal diagnosis of a mental health disorder</i>	.28	.754	.007
7. I have the <i>adequate skills and training</i> to assess and diagnose mental health disorders in adults with an intellectual disability	2.45	.093	.056
8. I have <i>adequate resources</i> in my current workplace to facilitate assessment and diagnosis of mental health disorders in adults with an intellectual disability	4.41	.015	.096

Given the questionnaire items were developed specifically for this study, exploratory factor analysis revealed close to adequate internal consistency with a Cronbach alpha coefficient reported at .64 for the full 25-items. The questionnaire items were initially structured into four areas: training, mental health care of adults with dual disabilities, prevalence of mental health concerns in adults with ID, and assessment and diagnosis; hence, confirmatory factor analyses were conducted to test if items loaded onto these factors. After varimax rotation, items loaded on four factors. However, as these factors did not appear to relate directly to the prescribed four areas, no further analyses were conducted. Accordingly, individual statements from the questionnaire were used to investigate the study's aims.

Results

Analyses pertaining to participant characteristics were conducted prior to hypotheses testing. Government disability, non-government disability (NGO) and private practice psychologists differed significantly in years of experience as a psychologist, $F(5, 103) = 2.59$, $p = .030$, partial $\eta^2 = .112$, years of experience in ID, $F(5,100) = 2.83$, $p = .020$, partial

$\eta^2 = .124$, educational qualifications, $\chi^2(4, n = 92) = 26.85, p < .0005$, and professional role, $\chi^2(6, n = 92) = 17.25, p = .008$, (see Table 3).

Table 3

Demographic Frequencies: Psychologists across Work Settings

	Government disability setting ($n = 55$)	Non- government organisation ($n = 22$)	Private practice ($n = 15$)	p value
Gender				.925
Male	16.4%	13.6%	20.0%	
Female	83.6%	86.4%	80.0%	
Professional role				.008
Provisional psychologist	3.6% ^a	22.8% ^b	0% ^a	
Generalist Psychologist	69.0% ^a	63.6% ^a	60.0% ^a	
Clinical Psychologist	12.7% ^{a,b}	0% ^b	33.3% ^a	
Other	14.6% ^a	13.6% ^a	6.7% ^a	
Highest qualification				<.0005
Bachelors	55.0% ^a	73.0% ^a	20.0% ^b	
Masters	44.0% ^a	23.0% ^a	40.0% ^a	
Higher degree	1.0% ^a	4.0% ^a	40.0% ^b	
	$M(SD)$	$M(SD)$	$M(SD)$	
Years of experience	9.65(8.85) ^a	9.02(9.68) ^a	18.00(10.5) ^b	
Years of experience in ID	11.31(8.13) ^a	9.70(9.24) ^a	20.13(11.83) ^b	
Years in current role	6.39(5.86)	5.16(4.22)	9.47(8.90)	

Note. Health settings, specialist settings and other settings were omitted from analyses as sample sizes were too small to make meaningful comparisons.

Column means with the same subscript letters (^{a, a}, or ^{b, b}) do not differ significantly from each other at the .05 level. Column means with different subscript letters (^{a, b}) differ significantly at the .05 level)

These variables were therefore included as covariates in subsequent analyses involving work setting (aim one). Given the small proportion of psychologists recruited from public health settings ($n = 4$), meaningful comparisons between psychologists in government disability versus public health settings could not be conducted.

Provisional, generalist and clinical psychologists differed significantly in years of experience as a psychologist, $F(3, 105) = 9.71, p < .0005$, partial $\eta^2 = .217$, years of experience in ID, $F(3, 102) = 4.06, p = .009$, partial $\eta^2 = .107$, years in current work role, $F(3.104) = 2.72, p = .039$, partial $\eta^2 = .073$ (See Table 4 for further t-test statistics), education qualifications, $\chi^2(6, n = 109) = 27.64, p < .0005$, and work setting, $\chi^2(15, n = 109) = 26.19, p = .036$. (See Table 4 for Chi-square statistics). These variables were therefore also included as covariates in subsequent analyses when evaluating differences between the professional roles (aim one).

Table 4

Demographic Frequencies: Comparisons between Professional Roles

	Provisional Psychologist ($n = 8$)	Generalist Psychologist ($n = 71$)	Clinical Psychologist ($n = 16$)	p value
Gender				.646
Male	12.5%	16.9%	6.3%	
Female	87.5%	83.1%	93.8%	
Highest professional qualification				<.0005
Bachelors	100% ^a	60.6% ^b	0% ^c	
Masters	0%	31.0%	81.3%	
Higher degree	0%	8.5%	18.8%	
Work setting				.003
Government disability setting	25.0% ^a	53.5% ^a	43.8% ^a	
Non-government organisation	62.5% ^a	19.7% ^b	0% ^b	
Private practice	0% ^a	12.7% ^a	31.3% ^b	

	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)
Years of experience	0(0) ^a	10.49(8.46) ^b	14.19(10.30) ^b
Years of experience in ID	3.75(2.98) ^a	11.90(9.21) ^b	15.07(11.04) ^b
Years in current role	1.69(0.70) ^a	6.51(5.75) ^{a,b}	8.91(7.74) ^b

Note. Column means with the same subscript letters (^a, ^a, or ^b, ^b) do not differ significantly from each other at the .05 level. Column means with different subscript letters (^a, ^b) differ significantly at the .05 level).

Perceptions on Clinical Competencies

Overall, 65% of psychologists ($n = 68$) reported more confidence in identifying mental health *symptoms* in adults with ID compared to *making a formal diagnosis* of a mental health disorder based on DSM-IV-TR criteria (American Psychiatric Association, 2000). However, only half the sample (51%, $n = 54$) reported adequate skills and training to assess and diagnose mental health disorders in adults with ID. Similarly, almost half the sample (49%; $n = 52$) considered themselves specialists in mental health and ID in their current work roles. No significant differences between clinical, generalist and clinical psychologists were found in the above statements (*all p 's* > .01).

Work setting had a significant effect on perceptions of adequacy of disability services in addressing mental health concerns of adults with dual disabilities, $F(2, 72) = 5.30$, $p = .007$, partial $\eta^2 = .113$. Post hoc pairwise analyses revealed that compared to psychologists from NGO settings ($M = 3.29$, $SD = 1.14$), those from government disability settings ($M = 3.85$, $SD = .99$) perceived disability settings as being less adequate in addressing mental health concerns of adults with ID, $F(2, 78) = 9.57$, $p = .006$, partial $\eta^2 = .20$ than did NGO psychologists. However, work setting did not influence psychologist's perceptions of their specialist role in mental health and ID and the adequacy of their skills in mental health assessment in adults with ID (p 's > .01; see Table 2). Overall, less than one fifth of participants agreed or strongly agreed that four-year trained psychologists in either

mainstream mental health (11%; $n=12$) or disability services (17%; $n=18$) were skilled in mental health assessment and diagnosis for adults with ID.

Adequacy of Workplace Supports

Forty three percent ($n = 45$) of psychologists surveyed agreed or strongly agreed with the statement that their work setting provided sufficient on-the-job training in dual disabilities. Similar ratings were found between professional roles and work settings. Work setting had a significant effect on perception of adequacy of workplace resources, $F(2, 72) = 6.72, p = .002$, partial $\eta^2 = .139$. Post hoc pairwise analyses revealed psychologists in private practice ($M = 2.29, SD = 0.27$), reported higher agreement ratings on the adequacy of workplace resources for mental health assessment, $F(2, 78) = 10.70, p = .003$, partial $\eta^2 = .22$, than did psychologists working in government disability settings ($M = 3.28, SD = 1.03$).

Perceived Training Needs

Only 36% ($n = 39$) of participants stated their academic training included specific training in ID. From the 39 participants who received academic training, 28% ($n = 11$) received a workshop, 41% ($n = 16$) underwent specialist placements, 62% took a course unit/partial course unit in intellectual disabilities, 72% ($n = 28$) received a minimum of a partial lecture and 5% ($n = 2$) received other forms of academic training. In regards to workplace training in dual disabilities, 59% ($n = 64$) attended conferences, 69% ($n = 74$) attended workshops, 78% ($n = 84$) received clinical supervision, 87% ($n = 94$) sought research literature, and 11% ($n = 12$) received other forms of workplace training.

The majority of clinicians (86%, $n = 90$) indicated they would like further training in mental health and ID. Common themes were generated amongst four-year and six-year qualified psychologists. Both groups identified online access to training and workshops as the most desirable formats of training. Four-year qualified psychologists also reported

assessment and treatment of mental health conditions in adults with ID as an important focus for training. Provisional psychologists identified requiring training in specialised assessment tools, while generalist psychologists required online and workshop formats, assessment and treatment of mental health for people with ID, and guidelines on assessment of mental health in people with ID. Clinical psychologists reported online, workshop and conference formatting as most important.

Discussion

This study is the first Australian survey exploring clinical competencies and perceived training needs of clinical psychologists compared with generalist and provisional psychologists working in the field of ID. The objective was to investigate the perceptions of clinical competencies and training needs when working with adults with co-morbid ID and mental health concerns. Contrary to predictions, clinical psychologists did not rate themselves higher on being a specialist in MH and ID nor in possessing more skills and resources in assessment and diagnosis compared to generalist and provisional psychologists. This is surprising given that clinical psychologists trained in accredited institutions receive specialist formal training in assessment, diagnosis and treatment of mental health disorders, and hence would be expected to show more competence in mental health assessment (Newnham & Page, 2010). However, only a small percentage of the sample agreed overall that four-year qualified psychologists are skilled in assessing and diagnosing mental health concerns in people with ID.

Work setting had a significant effect on the perceptions of adequacy of workplace resources in working with adults with ID. Interestingly, psychologists from government disability settings, a work setting assumed to be more resourced, reported lower ratings on the adequacy of workplace resources for mental health assessment and diagnosis of people with ID compared to psychologists working in private practice. It is possible that private

practices may be more able to allocate funds to purchase resources while psychologists from government agencies are dependent on the funding allocated to the organisation and may therefore perceive less control over resource provision. Whether psychologists across work settings differed on their awareness and accessibility to specialist resources is beyond the scope of this paper and will be addressed separately.

Psychologist's work setting did not influence perceptions of the specialist role in mental health and ID or perceived adequacy of their skills in mental health assessment in adults with ID. It is unclear how the psychologists surveyed defined the terms 'specialist' and 'mental health assessment' as these terms were not pre-defined in the questionnaire and are therefore subject to interpretation based on participants' clinical roles within each work setting. Whether this influenced the lack of significant findings will require further investigation. Ratings on the provision of sufficient on-the-job training in ID and co-morbid mental ill health were also similar across work settings. However, it should be noted that psychologists on average rated this item as 'neither agree nor disagree' suggesting that specialist training in mental health and ID may be largely unavailable.

Findings from the second aim supported the hypothesis that psychologists in general receive limited formal training in ID and limited ongoing training in mental health and ID in their current workplace. Importantly, a majority of psychologists (85%) indicated a need for specialist training in this area. Findings suggest that less than half of psychologists surveyed receive some form of academic training in ID, training which varied in depth and duration. This outcome highlights the need for further workplace training in mental health and ID to suit the specific needs of psychologists in the field. At present, diagnostic overshadowing continues to pose barriers to mental health service access for people with ID (Bennett, 2014). It is envisioned that with improved clinical competencies, identification of mental health conditions by psychologists will subsequently improve access

to mental health services for people with ID. Given the limited training in ID reported by psychologists within the Australian postgraduate psychology curriculum, specialised training in mental health assessment for people with ID should be an important focus within the workplace. Training in online and workshop formats focusing on mental health assessment and diagnosis incorporating practice guidelines and use of specialised assessment tools for people with ID was identified as necessary by psychologists working in this field. An online training module focusing on the components of mental health assessment for psychologists working with people with ID beyond what has been provided currently via the free on-line training in dual disabilities (Department of Developmental Disability Neuropsychiatry, 2013) would improve access to training for psychologists in both urban and rural areas. Clinical psychologists may also benefit from advanced training in case formulation and mental health diagnosis for people with ID. It is envisioned that with increased specialised training, enhanced clinical competencies, and confidence in addressing the mental health needs of people with ID will improve for psychologists working in public mainstream settings.

Study Strengths, Limitations and Implications

Research into the limitations of psychiatry training in Australia has led to many initiatives in an attempt to increase competency in ID such as a competency based advanced training programme in ID which was introduced to psychiatric registrars (Johnson et al., 2013). Similarly, it is envisioned this study has the potential scope to start the momentum for developments of specialised training of psychologists in mental health and ID. With the Australian NDIS comes the inevitable need to restructure service models and professional roles, given the widening scope of consumers meeting criteria for services. Based on the findings of the study, psychologists in general reported limited confidence in mental health diagnosis of adults with ID and perceived limited adequacy of both mainstream health and

disability services in mental health assessment and diagnosis for people with ID. Given this, it is an opportune time to provide advanced training to meet the increased demand for mental health services for people with ID. In fact, strengthening current public mental health services may hold more importance and relevance than developing specialist mental health and ID services (Hemmings, Bouras & Craig, 2014). Hemmings and colleagues (2014) suggested that specialists in the field of mental health and ID may be best situated directly within mainstream services rather than operating as separate entities. This model of service may be compatible with the way in which disability services will be delivered under the Australian NDIS.

One limitation of this study is the modest number of psychologists recruited. Although the percentage of registered psychologists in Australia working with adults with ID is unknown, the modest sample size may have compromised the power for group comparisons conducted between professional roles and work settings. For instance, clinical psychologists provided the highest agreement ratings on self-perceived role as a specialist in ID and mental ill health and rated themselves higher on skills and resources in conducting mental health assessments and it is likely that higher representation of this group would lead to significant findings. Comparisons between psychologists in public health and disability settings were also not possible due to the small representation of public health psychologists. Furthermore, information on previous work settings was not obtained and it is possible that participating psychologists may have worked across a variety of work settings therefore potentially confounding work setting comparisons. Information on the presence of interdisciplinary teams within current work settings may have impacted on psychologists' clinical practices and capacity to collaborate with others. .

It was beyond the scope of this paper to investigate previous training in ID separate from training in mental health assessment. It is possible that prior training in ID and mental

health assessment may impact on clinical competence of psychologists conducting mental health assessments with individuals with ID. Furthermore, with all self-report studies comes the limitation of possible effects of social desirability. It is therefore possible that psychologists motivated to partake in the study may hold special interest in the area of ID and mental ill health and more specialist skills in comparison to other psychologists in this field.

It was beyond the scope of this study to explore how mental health assessments for people with ID are conducted by psychologists and compliance with best practice. This will require further investigation. Given the lack of national guidelines found in Australia which is similar to the UK and US; and the heterogeneous nature of qualifications and expertise of psychologists working in ID, it is likely that mental health assessment will vary as a result. How the workplace culture impacts on psychologists' perceived clinical competencies given professional role limitations remains unknown. Future studies examining workplace impact on implementation of best practice of mental health assessment for people with ID would assist in greater understanding of the psychology profession in the evolving field of ID.

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APPENDIX A

Section One: DEMOGRAPHIC INFORMATION QUESTIONNAIRE

Please answer all questions as accurately as possible. Please select one response by marking the box that best describes you unless otherwise specified.

1. What is your gender? ☐ Male ☐ Female

2. State currently working as a psychologist:

<input type="checkbox"/> NSW	<input type="checkbox"/> ACT	<input type="checkbox"/> Victoria	<input type="checkbox"/>
Queensland	<input type="checkbox"/> Northern Territories	<input type="checkbox"/> South Australia	<input type="checkbox"/> Western
Australia	<input type="checkbox"/> Tasmania		

3. Number of years registered as a psychologist? (Please state if currently provisionally registered)_____

4. Highest level of professional psychology training
 - ☐ Bachelors degree in or majoring in psychology
 - ☐ Currently undertaking Masters degree in psychology
 - ☐ Clinical
 - ☐ Education and Developmental
 - ☐ Forensic
 - ☐ Neuropsychology
 - ☐ Counselling
 - ☐ Other: Please specify_____
 - ☐ Completed Masters degree in psychology:
 - ☐ Clinical
 - ☐ Education and Developmental
 - ☐ Forensic
 - ☐ Neuropsychology
 - ☐ Counselling
 - ☐ Other: Please specify_____
 - ☐ Currently undertaking professional Doctorate degree in psychology (NOT Doctor of Philosophy)
 - ☐ Completed professional Doctorate degree in psychology (NOT Doctor of Philosophy)
 - ☐ Currently undertaking Combined Masters/PhD program
 - ☐ Completed Combined Masters/PhD program

5. Current work setting as a psychologist:
 - ☐ Government disability agency
 - ☐ Non-government disability agency
 - ☐ Local area community health centre
 - ☐ Local area hospital
 - ☐ Specialist mental health and intellectual disability service
 - ☐ Private practice
 - ☐ Other. Please specify_____

6. Current professional title/role in current work setting:
 - ☐ Provisional psychologist
 - ☐ Psychologist
 - ☐ Clinical Psychologist
 - ☐ Specialist Psychologist
 - ☐ Behaviour Support Practitioner (or similar title) (Clinicians with training and experience in the provision of behavioural support and intervention for people with intellectual disabilities)
 - ☐ Other: Please specify _____

7. Number of years in current professional role _____

8. Which would best describe the nature of your *primary* professional role?
 - ☐ Assessment. Please specify type of assessment:
 - ☐ Developmental/ intellectual
 - ☐ Neuropsychological
 - ☐ Behavioural
 - ☐ Diagnostic
 - ☐ Other. Please specify _____
 - ☐ Intervention e.g. CBT, Psychotherapy, behaviour intervention
 - ☐ Consultation
 - ☐ Acute mental health
 - ☐ Other: Please specify _____

9. You have been trained in the following therapeutic modalities:
 - ☐ Cognitive behavioural therapy
 - ☐ Applied behavioural therapy
 - ☐ Family systems therapy
 - ☐ Narrative therapy
 - ☐ Mindfulness based therapies. Please specify type e.g. DBT, MBCT, ACT, MBSR _____
 - ☐ Other modalities. Please specify _____

10. You currently utilise the following therapeutic modalities in your current professional role:
 - ☐ Cognitive behavioural therapy
 - ☐ Applied behavioural therapy
 - ☐ Family systems therapy
 - ☐ Narrative therapy
 - ☐ Mindfulness based therapies. Please specify type e.g. DBT, MBCT, ACT, MBSR _____
 - ☐ Other modalities. Please specify _____

11. In your current professional role, please rate the proportion of time (as a percentage out of 100) spent in a typical week *in each of the following areas (excluding administrative time)*:
 - ☐ Assessment. Please specify type of assessment:
 - ☐ Developmental/ intellectual _____
 - ☐ Neuropsychological _____
 - ☐ Behavioural _____

- ☐ Diagnostic _____
- ☐ Other. Please specify _____
- ☐ Intervention e.g. CBT, Psychotherapy, behaviour intervention _____
- ☐ Consultative _____
- ☐ Acute mental health _____
- ☐ Other: Please specify _____

12. How many hours of professional *direct contact* in a *typical week* do you have working with *people with intellectual disabilities* in your *current professional role*?

13. What proportion of your caseload involves *assessment* of people with an *intellectual disability*? (As a percentage out of 100)

14. What proportion of your caseload involves *treatment* of people with an *intellectual disability*? (As a percentage out of 100)

15. What proportion of your client caseload have an *intellectual disability with mental health issues (including those with sub clinical presentations)*? (As a percentage out of 100)

16. Overall how many years of professional experience have you had working with people with intellectual disabilities? (This may include time spent in other professions besides psychology)

Section Two

For the purpose of this survey, the following definitions will be used:

- **Mental disorders** refer to axis I and axis II disorders listed in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV), EXCLUDING Pervasive Developmental Disorders such as Autism Spectrum Disorders, learning disorders, motor skills disorders, communication disorders, mental retardation and cognitive disorders such as dementia.
- In the International Statistical Classification of Diseases and Related Health Problems. 10 Revision (ICD-10) this EXCLUDES Pervasive Developmental Disorders, mental retardation, disorders of psychological development and specific developmental disorders of scholastic skills, specific developmental disorders of speech and language, dementia and other cognitive disorders

- **Intellectual disability refers to:**
Intellectual functioning assessed on a standardised test of intellectual functioning of approximately 70 or below.
Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.)
The onset is before age 18 years. (DSM-IV TR)
- **Dual disability** refers to individuals diagnosed with both an intellectual disability and a mental disorder.
- **Challenging behaviours** refers to behaviours '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 or delay access to and use of ordinary community facilities' (Emerson et al., 1987).
- **Evidence-based practice** refers to practice informed by current research literature
- **Best practice** refers to practice guided by a combination of current research literature and expert consensus

Please indicate to what extent you agree or disagree with the following statements on a 5 – point scale ranging from strongly agree to strongly disagree.

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	1	2	3	4	5
Training					
Psychologists <i>in my current work setting</i> receive sufficient on the job training to manage people with <i>dual disabilities</i>					
Psychologists receive sufficient <i>academic training</i> in their masters degree to manage people with <i>dual disabilities</i>					
Training in dual disability should be offered during <i>academic training in the masters degree</i> in psychology					
Continual training in dual disability is supported and/or encouraged in my current workplace					

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	1	2	3	4	5
Mental health care of adults with dual disabilities					
Addressing mental health concerns in people with dual disabilities is the primary responsibility of <i>mainstream mental health</i> settings					
<i>Mainstream mental health services</i> can adequately address mental health concerns of adults with dual disabilities					
<i>Disability services</i> can adequately address mental health concerns of adults with dual disabilities					
Services <i>specialising in dual disability</i> are required to support the mental health needs of people with dual disabilities					
Collaboration between mental health and disability services is essential in meeting the mental health needs of people with dual disabilities					
There are clear <i>guidelines for best practice</i> in the <i>assessment</i> of mental disorders in adults with intellectual disabilities					
There are clear <i>guidelines for best practice</i> in the <i>treatment</i> of mental disorders in adults with intellectual disabilities					
Clinical assessment of mental disorders by psychologists in my current work setting is guided by evidence-based practice					
My current work place supports the use of evidence-based practice for work with people with dual disabilities					

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	1	2	3	4	5
It is important to be guided by evidence-based practice when working with people with dual disabilities					
Evidence-based practice derived from research settings can be directly applied in my current clinical setting					
I consult current research literature to assist in my work with people with dual disabilities					
Prevalence of mental health concerns in adults with intellectual disability					
Adults who present to mental health services do so more because of <i>challenging behaviours</i> rather than due to <i>mental health symptoms</i>					
Adults with intellectual disabilities are <i>less likely</i> to experience mental health concerns compared with adults without intellectual disabilities					
Challenging behaviours are distinct from mental health symptoms in adults with <i>dual disabilities</i>					
Assessment and diagnosis					
<i>Clinical psychologists in mainstream mental health services</i> are qualified and skilled in assessing and diagnosing mental disorders in adults with intellectual disability					

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	1	2	3	4	5
<i>Fourth year trained psychologists in mainstream mental health services</i> are qualified and skilled in assessing and diagnosing mental disorders in adults with intellectual disability					
<i>Fourth year trained psychologists in disability services</i> are qualified and skilled in assessing and diagnosing mental disorders in adults with intellectual disability					
Only <i>psychiatrists with experience in dual disability</i> are qualified and skilled in assessing and diagnosing mental disorders in adults with intellectual disability					
Specialist assessment tools/rating scales (those specifically designed or modified for the intellectual disability population) are required in order to accurately assess mental health concerns in adults with intellectual disability					
It is important to work in collaboration with other mental health professionals involved with the client from other settings in conducting mental health assessments for adults with intellectual disabilities					
Assessment of mental health concerns in adults with intellectual disability are generally more <i>symptomatic</i> than <i>syndrome based</i>					
I am aware of differential diagnoses typical of adults with intellectual disability when assessing for specific mental disorders					

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
	1	2	3	4	5
Specialised assessment tools/resources add value to the assessment of specific mental disorders in adults with intellectual disability					
Adults with differing levels of intellectual disability may present mental health symptoms differently					
Assessment of mental health concerns in adults with intellectual disabilities requires a <i>multi-modal</i> and <i>multi-disciplinary</i> approach					
I would feel more confident identifying <i>mental health symptoms</i> in adults with intellectual disabilities compared with making a <i>formal diagnosis of a mental disorder</i>					
I have the <i>adequate skills and training</i> to assess and diagnose mental disorders in adults with intellectual disabilities					
I have <i>adequate resources</i> in my current workplace to facilitate assessment and diagnosis of mental disorders in adults with intellectual disabilities					
I am recognised as a specialist in mental health and intellectual disability in my current clinical role					

Please read each question carefully and answer all questions as accurately as possible.

1. Did your academic training as a psychologist include training in intellectual disabilities?

☐ Yes ☐ No

If yes, in what format? (Choose as many categories that apply)

- ☐ Lecture
- ☐ Series of lectures
 - ☐ One lecture
 - ☐ Part of a lecture
- ☐ Workshop. Specify number of days_____
- ☐ Specialised placement. Specify number of days_____
- ☐ Course unit or part of a unit. What was the unit name?_____
- ☐ Other: Please describe_____

2. In your current professional role, what further training have you sought in the area of dual disability? (Choose as many categories that apply)

- ☐ Conference. Please specify frequency per year_____
- ☐ Workshops. Please specify frequency per year_____
- ☐ Further reading of literature. Please specify frequency per year_____
- ☐ Supervision. Please specify frequency_____
- ☐ Other: Please specify _____
Please state frequency_____
- ☐ None

3. Would you benefit from further training in dual disability?

☐ Yes ☐ No

If yes, please describe below how these training needs can best be met:

- 4a. Are there current barriers to the implementation of best practice in assessing mental health concerns in people with intellectual disabilities in your current work setting?

☐ Yes ☐ No

If yes, please describe below:

- 4b. If yes, what are your suggestions regarding ways to overcome these barriers?

5. Does your current professional role involve *direct assessment of mental health concerns* in adults with intellectual disabilities?

- ☐ Yes ☐ No

If yes, please complete next section.

If no, thank you for completing this survey.

**Section Three: Assessment of Mental Health Concerns in Adults with
Intellectual Disabilities**

Please read each question carefully and answer all questions as accurately as possible.

1a. Which of the following mental health concerns have you encountered in your clinical experience with adult clients with an intellectual disability? (You may choose more than one category)

- ☐ Mood disorder
- ☐ Anxiety disorder
- ☐ Psychosis
- ☐ Personality disorder
- ☐ Eating disorder
- ☐ Other: Please specify_____

b. Of the mental health concerns you have identified, which one have you encountered the most often?

- ☐ Mood disorder
- ☐ Anxiety disorder
- ☐ Psychosis
- ☐ Personality disorder
- ☐ Eating disorder
- ☐ Other: Please specify_____

2a. In your current work setting/team, are mental disorder diagnoses made for adults with intellectual disabilities?

- ☐ Yes

If so, which professional is most likely to make a mental disorder diagnosis for adults with intellectual disabilities? _____

- ☐ No

If not, how often are adult clients with intellectual disabilities referred on for their mental health needs?

- ☐ Never
- ☐ Approximately 25% of the time
- ☐ Approximately 50% of the time
- ☐ Approximately 75% of the time
- ☐ 100% of the time

b. Rank the professionals/services from most to least likely to receive these referrals (with 1 being most likely and 3 being least likely):

- ☐ Psychiatrist specialising in intellectual disability
- ☐ Specialist mental health and intellectual disability assessment team
- ☐ Other. Please specify_____

3. Are there any time constraints placed on your initial assessment of psychological problems for each client in your current work setting?

- ☐ Yes. If yes, please briefly describe constraints imposed_____
- ☐ No

4. In your current professional role, which of the following professionals have you collaborated with in your mental health assessment of your adult clients with intellectual disability with mental health concerns for case formulation and diagnosis? (You may choose more than one category)

- ☐ GP
- ☐ Psychiatrist
- ☐ Other psychologists working with the client
- ☐ Behaviour support practitioners (Clinicians with tertiary qualifications in Psychology, Special Education, Speech Pathology, Social Work or other relevant discipline, and /or training and experience in the provision of behavioural support and intervention to people with intellectual disabilities)
- ☐ Other: Please specify_____

5. In your current professional role, which of the persons listed below do you have the opportunity to gather further information from about your client during the initial assessment phase? (Choose as many categories that apply)

- ☐ Client
- ☐ Parents/ primary carers
- ☐ Other family members
- ☐ Direct support staff
- ☐ General Practitioner
- ☐ Psychiatrist
- ☐ Speech Pathologist
- ☐ Occupational Therapist

- ☐ Physiotherapist
- ☐ Social worker
- ☐ Case manager
- ☐ Other professionals working with client. Please specify: _____

6. In your current role, what methods have you utilised in your assessment of mental health concerns in adult clients with dual disability? (Choose as many categories that apply)

- ☐ Clinical interview with client
- ☐ Clinical interview with family/carers
- ☐ Structured clinical interview schedules
- ☐ Semi-structured clinical interview schedules
- ☐ Checklists/rating scales
- ☐ Behavioural data completed by carers/staff
- ☐ Direct observation of client in interview setting
- ☐ Direct observation of client in settings outside of the interview setting. Please specify _____
-
- ☐ Specialised assessment tools/rating scales (those specifically designed or modified for the intellectual disability population)
- ☐ Functional analysis of behaviour
- ☐ Other: Please specify _____

7. During the assessment phase of mental health problems for adults with intellectual disabilities in my current work setting, I have the opportunity to apply special considerations when seeing a client with an intellectual disability (in comparison to what I would do typically with clients without an intellectual disability) to: (Choose as many categories that apply)

- ☐ The interview setting. Please describe briefly: _____
- ☐ Communication with my client. Please describe briefly _____
- ☐ Type and variety of informants. Please describe briefly _____
- ☐ The duration of sessions. Please describe briefly: _____
- ☐ Interview style. Please describe briefly: _____
- ☐ History taking of the client. Please describe briefly: _____
- ☐ Other special considerations. Please describe briefly: _____

8. Which of the following specialist resources and tools in mental health assessment are you *aware of*? (Choose as many categories that apply)

- ☐ Diagnostic Manual-Intellectual Disability (DM-ID)
- ☐ Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD)
- ☐ Psychiatric assessment schedule for adults with developmental disabilities(PASS-ADD)/ Mini-PASS-ADD checklist

- ☐ Psychopathology Inventory for Mentally Retarded Adults (PIMRA)
- ☐ Reiss Screen for Maladaptive Behaviour
- ☐ Developmental Behaviour Checklist (DBC)
- ☐ Diagnostic Assessment of the Severely Handicapped (DASH II)
- ☐ Self Report Depression Questionnaire (SRDQ)
- ☐ Glasgow Depression Scale for People with a Learning Disability (GDS-LD)
- ☐ Glasgow Anxiety Scale for People with Intellectual Disability (GAS-ID)
- ☐ Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability
- ☐ Other. Please specify_____

9. Which of the following specialist resources and tools *are available to you* in your *current work setting* to aid you in mental health assessments? (Choose as many categories that apply)

- ☐ Diagnostic Manual-Intellectual Disability (DM-ID)
- ☐ Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD)
- ☐ Psychiatric assessment schedule for adults with developmental disabilities(PASS-ADD)/ Mini-PASS-ADD checklist
- ☐ Psychopathology Inventory for Mentally Retarded Adults (PIMRA)
- ☐ Reiss Screen for Maladaptive Behavior
- ☐ Developmental Behaviour Checklist (DBC)
- ☐ Diagnostic Assessment of the Severely Handicapped (DASH II)
- ☐ Self Report Depression Questionnaire (SRDQ)
- ☐ Glasgow Depression Scale for People with a Learning Disability (GDS-LD)
- ☐ Glasgow Anxiety Scale for People with Intellectual Disability (GAS-ID)
- ☐ Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability
- ☐ Other. Please specify_____

10. Which of the following specialist resources and tools *have you used* in your *current work setting* to aid you in mental health assessments for adults with intellectual disabilities? (Choose as many categories that apply)

- ☐ Diagnostic Manual-Intellectual Disability (DM-ID)
- ☐ Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD)
- ☐ Psychiatric assessment schedule for adults with developmental disabilities(PASS-ADD)/ Mini-PASS-ADD checklist
- ☐ Psychopathology Inventory for Mentally Retarded Adults (PIMRA)
- ☐ Reiss Screen for Maladaptive Behavior
- ☐ Developmental Behaviour Checklist (DBC)
- ☐ Diagnostic Assessment of the Severely Handicapped (DASH II)
- ☐ Self Report Depression Questionnaire (SRDQ)
- ☐ Glasgow Depression Scale for People with a Learning Disability (GDS-LD)
- ☐ Glasgow Anxiety Scale for People with Intellectual Disability (GAS-ID)

- ☐ Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability
- ☐ Other. Please specify_____

11. Of the tools/resources highlighted *as used* in your current workplace, *how often* are they used in your assessment of clients with mental health concerns and intellectual disability?

- ☐ Approximately 25% of *dual disability client caseload*
- ☐ Approximately 50% of *dual disability client caseload*
- ☐ Approximately 75% of *dual disability client caseload*
- ☐ 100% of *dual disability client caseload*

12. Identify the reasons certain tools/resources listed have NOT been made available in your current workplace. (Choose as many categories that apply)

- ☐ Lack of funding
 - ☐ Time constraints with assessment phase
 - ☐ Unaware of tools/resources available
 - ☐ Lack of support from management
 - ☐ Mainstream resources are sufficient
 - ☐ Other reasons: Please describe briefly
-

Bridging Chapter following Chapter 2

The first paper arising from Phase one of this research focused on investigating the clinical attitudes, prior training in intellectual disabilities and training needs of Australian psychologists working with adults with an intellectual disability using an on-line national survey. The outcomes from this initial paper provide an overall view of how Australian psychologists in intellectual disabilities perceive their clinical competence and practice. Given the limited literature currently available on the subject of psychology practice in dual disabilities, such investigations are required before delving into a more detailed account of clinical practices and experiences of psychologists working in this field.

Regarding psychologists' self-perceived views of clinical competency, it was found that a majority of psychologists reported more confidence in identifying mental health symptoms in adults with an intellectual disability compared to making a formal diagnosis of a mental health disorder. In addition, only half of the sample reported having adequate skills and training to assess and diagnose mental health disorders in adults with an intellectual disability, or considered themselves specialists in dual disabilities. Given that half of those surveyed reported confidence in conducting mental health assessments with individuals with an intellectual disability, how such assessments are conducted in practice and within the context of one's work role warrants investigation. Furthermore, given that most psychologists surveyed in this first phase stated that four-year trained psychologists in either mainstream mental health or disability services do not possess specialist skills to conduct mental health assessment and diagnosis adults with an intellectual disability, it would be important to examine psychologists' clinical practices when conducting mental health assessments and also explore what psychologists consider as best practice in this specialist field.

It is noteworthy, that chapter two findings suggest there is a larger proportion of four year trained psychologists working in the disability sector compared with those with postgraduate and higher degree qualifications. Psychologists in the health sector may have a higher proportion of master and higher degree qualified psychologists. Given this, examining whether differences in clinical practices exist between four year and master qualified psychologists and between work settings would provide insight into differences in professional roles and service operations.

In this initial study, interestingly, the majority of psychologists across work settings and level of qualifications also reported the need for further training in dual disabilities. Given the high demand for specialist training, it would be important to examine whether current expertise and practices are in line with available national and international best practice. Regarding differences between work settings, only perceptions of the adequacy of workplace resources in dual disabilities were found between participants working in government disability agencies and private practices. Following on from these findings, further investigations are needed into whether such workplace differences impact on assessment practices of psychologists and their ability to implement best practices as determined by currently available practice guidelines.

Given the above, the aim of the second paper based on the initial phase study was to investigate the current assessment practices of Australian psychologists working with adults with an intellectual disability and whether they align with Australian and international best practice standards. Different aspects of mental health assessment were explored including referral patterns, application of special considerations, utilisation of specialist resources and collaboration with others during the assessment process. This next study also examined whether psychologists experienced barriers in their workplace regarding evidence based practice implementation. Collectively, the outcomes from this first phase from the current

program of research will provide a more comprehensive view on attitudes and implementation of evidence based practice by Australian psychologists working in the intellectual disability field.

Chapter 3: Phase 1 Paper 2

Clinical Practices and Barriers to Evidence based Practice of Psychologists Working with Adults with Intellectual Disability and Co-morbid Mental Ill Health

Joyce Man¹, Maria Kangas¹, Julian Trollor² and Naomi Sweller^{3,2}

1 Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, Australia

2 Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW, Sydney, Australia

3 Department of Psychology, Faculty of Human Sciences, Macquarie University, Sydney, Australia

* Manuscript submitted

² This is to confirm Joyce Man is the first author and has completed all field work, data analysis and the first full draft of this paper.

Abstract

Background: Evidence based practice (EBP) has not been well established in the area of intellectual disability (ID) and co-morbid mental ill health. Some attempts in the form of policies and practice guidelines have been made.

Specific aims: The aim of this study was to investigate clinical practices of Australian psychologists working with adults from this specialist population and to explore barriers to EBP implementation.

Method: One hundred and two psychologists completed a self-report online survey exploring barriers to EBP implementation. Sixty one psychologists completed questions relating to their practice including diagnostic practices, special considerations and use of specialist resources.

Findings: Psychologists reported many clinical practices that were in line with current national and international guidelines. However, the sample also reported a number of practical barriers to implementing best practice recommendations.

Discussion: Implications for training in mental health assessment and diagnosis and suggestions for system-wide support in delivering best practice are discussed.

Keywords: Best practice, evidence-based, guidelines, intellectual disabilities, mental health

Introduction

Individuals with intellectual disability (ID) have the right to access mental health services that cater to their needs. Despite this, examples of mental health service provision for individuals with ID which are based on best practice principles are few and far between in Australia (Bennett, 2014). One major barrier involves the limited guidance on evidence based practices (EBP) available on mental health service delivery for clinicians working with this population. At present, EBP, defined as the ‘integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences’ (APA Presidential Task Force, 2006) is a growing area in the field of ID. Evidence for interventions for autism (Odom et al., 2010) and positive behaviour support for management of challenging behaviours (e.g. Grey & Hastings, 2005) for people with ID is emerging. Beyond this, however, evidence based treatments for people with ID are not well established; partly due to poor research methodology and a lack of randomised controlled trials (Bhaumik et al., 2011). A paucity of research also exists in the area of assessment and treatment of mental health disorders for people with ID. Without clear EBP in this area, clinicians face ongoing challenges in maintaining the sensitivity and specificity of mental health assessment and treatment for individuals with ID.

In Australia, ongoing systemic barriers to appropriate mental health care for people with ID are evident. Bennett (2014) highlights the common occurrence of individuals falling between mainstream mental health and disability services, and advocates the need for specialist services with expertise in both ID and mental health conditions. Mental health assessment for individuals with ID is typically considered a specialist area requiring modification of mainstream practices in order to maximise the sensitivity and specificity of mental health disorder diagnoses (Morin et al., 2010). Furthermore, mainstream mental health practitioners are prone to diagnostic overshadowing when assessing individuals with

ID (Mason & Scior, 2004). Guidelines have been developed in the UK by the European Association for Mental Health in Mental Retardation (Deb et al., 2001). Most recently in Australia, best practice guidelines for working with people with ID have been further developed (e.g. Department of Developmental Disability Neuropsychiatry, 2016). Recently in the UK, the National Institute for Health and Care Excellence (NICE, 2016) also produced practice guidelines for working with mental health problems in individuals with ID.

In accord with the Australian Department of Developmental Disability Neuropsychiatry (2014) guidelines, reasonable adjustments to mainstream mental health practices are required to address the specific needs of individuals with ID and their families. In particular, use of specialist assessment tools and conducting comprehensive assessments in collaboration with carers and other professionals are just some of the practices considered best practice according to these guidelines. However, little is known whether such practices are commonplace amongst clinicians working in the ID field. Where clear national guidelines are limited, clinicians may draw on a combination of available literature, expert opinion and clinical experience to guide their work with people with ID. Given the need for reliable and valid mental health assessments for individuals with ID to facilitate access to mental health services, it is important to explore the nature and quality of assessment practices of psychologists and whether they align with current available guidelines.

Psychologists play a crucial role in meeting the mental health service needs of people with ID where EBP is paramount to psychological practice (Australian Psychological Society, 2006). The broader mainstream mental health literature highlights gaps between recommended and clinical practices. For example, in a US study, Jensen-Doss and Hawley (2010) examined multi-disciplinary clinician attitudes towards standardised mental health assessment tools and predictors of use. Doctorate-level clinicians and psychologists were found to report more positive ratings than other mental health professionals towards the use

of standardised assessment measures in relation to clinical judgment, psychometric qualities and practicality. Another US study revealed psychologists reported higher levels of self-efficacy and orientation towards EBP compared with social workers and marriage therapists (Parrish & Rubin, 2010). In contrast, a UK study with psychotherapists and intern clinical psychologists did not rate treatment manuals and evidence-based guidelines as influential to their clinical practice (Lucock et al., 2006). Focus groups with community health psychologists in the US viewed EBPs as too long, requiring substantial training and not applicable; all of which pose barriers to implementation (Nelson et al., 2006). In this latter study, the complexity of clients with multiple diagnoses and practitioner characteristics were also found to be major barriers to implementing EBPs.

A number of barriers with mental health service care provision for people with ID have also been highlighted. An Australian survey of general (medical) practitioner registrars found that 90% experienced difficulty in providing continuity of care, while two-thirds of respondents found it easier to establish ongoing doctor-patient relationships with individuals without ID (Cook & Lennox, 2000). Some specific barriers highlighted involved assessment and communication difficulties with the individual with ID, limitations surrounding consultation time, inadequate training and education in ID, maintaining continuity of care, and limited awareness of resources available (Cook & Lennox, 2000). In a further Australian survey, GPs continued to report more barriers to delivering quality health care to individuals with ID compared with non-ID patients (Phillips et al., 2004). Similarly, a survey conducted with Australian psychiatrists found that 75% considered anti-psychotics to be overused in controlling aggression and highlighted a lack of prescribing or best practice guidelines to serve the ID population at the time of the study (Edwards et al., 2007). In this latter study, 34% of surveyed psychiatrists also reported reluctance to work with adults with ID and admitted to treating from a symptom base as opposed to being diagnostically driven.

Gaps in the literature exist pertaining to the experiences of psychologists working in the field of ID and mental ill health. A recent Australian national survey of 109 psychologists working with adults with ID and co-morbid mental health problems found 65% of surveyed psychologists reported more confidence in identifying mental health symptoms than in formal mental disorder diagnosis (Man, Kangas, Trollor & Sweller, 2016) [*Chapter 2 of Dissertation*]. In fact, only half of the sample reported having adequate skills to assess and diagnose mental health disorders in adults with ID. The majority of the sample also indicated a need for further specialist training in mental health and ID. The current study builds on the findings from this survey by further exploring assessment and diagnostic practices and possible reasons for psychologists' limited confidence in mental health diagnosis.

Aims of the Study

Currently, there is a paucity of research pertaining to the clinical practice of psychologists working with people with ID and co-morbid ill mental health. The first aim of this study was to explore current assessment practices of psychologists working with adults with ID and whether they generally align with available Australian and international best practice standards. Given the first aim was exploratory, a range of clinical practices were examined including referring on for mental health diagnostic services, special considerations, use of specialist resources and collaboration with others during the assessment process. The second aim was to investigate existing barriers experienced by psychologists in implementing EBP when working with adults with ID and mental health concerns.

Method

Participant Characteristics

One hundred and two psychologists (86 females, 16 males) working with adults with ID took part in an online survey which was part of a larger scale study (Man et al., 2016) [*Chapter 2 of Dissertation*]. Psychologists were recruited from a range of disability and non-disability work settings (see Table 1). Psychologists reported variable clinical experience ranging from provisional registration to 37 years ($M = 10.63$ years, $SD = 9.54$), with the length of stay in the current work role ranging from one to 35 years ($M = 6.36$ years, $SD = 6.03$). Years of experience working with people with ID were also variable ranging from provisional registration to 42 years ($M = 11.96$ years, $SD = 9.41$). Psychologists with qualifications ranging from Bachelor degrees to Doctorate psychology degrees took part in the survey. Two thirds of the sample were generalist psychologists. The full sample completed the first two sections of the survey and was used to explore the second aim, that is, barriers to EBP implementation.

A sub-sample of 61 registered and provisionally registered psychologists who reported conducting mental health assessments with adults with ID within their current workplace met eligibility criteria to complete section three of the survey. This subsample was used specifically to examine assessment practices in line with aim one of the study. There were no significant differences in demographic characteristics between those psychologists who completed this section of the survey and those who did not.

Measures

The survey used was part of a larger national self-report survey (Chapter 2) consisting of three sections. Section one comprised demographic information; section two

Table 1

Sample Demographic Characteristics

Groups	Aim One Sample		Aim Two Sample	
	<i>N</i>	% total sample	<i>n</i>	% of sample
Work setting [Total]	61	100	102	61.0
Government disability	26	42.6	52	51.0
NGO	13	21.3	20	19.6
Private practice	13	21.3	14	13.7
Public/Community health	1	1.6	2	2.0
Specialist dual disability	1	1.6	2	2.0
Other	7	11.5	12	11.8
Qualification [Total]	61	100	102	100
Bachelors	31	50.8	54	52.9
Masters	22	36.1	39	38.2
Other higher qualification	8	13.1	9	8.8
Provisional psychologist	4	6.6	8	7.8
Generalist psychologist	39	63.9	67	65.7
Clinical Psychologist	11	18.0	14	13.7
Other (work role)	7	11.5	13	12.7
Years of experience [<i>M</i> (<i>SD</i>)]	11.65(9.70)		10.63 (9.54)	
Years in ID [<i>M</i> (<i>SD</i>)]	13.83(9.74)		11.96 (9.41)	
Years in current role [<i>M</i> (<i>SD</i>)]	7.18(6.52)		6.36(6.03)	

Note. For work settings, some participants worked in more than one setting, hence % > 100.

contained 25 statements in the areas of training, mental health care of adults with dual disabilities, prevalence of mental health concerns in adults with ID and assessment and diagnosis as well as open-ended questions on perceived training needs when working with people with ID and suggestions on how training needs could be best met. Section three

examined clinical practices of psychologists working with adults with ID and mental health disorders using multiple response questions. For the purposes of the current study, seven questions from section three of the questionnaire were administered to examine aim one. Questions related to referral practices and diagnosing clinicians within the workplace (Question 2), collaboration during the assessment process (Question 4), assessment methodologies (Question 6) and special considerations utilised (Question 7) as well as awareness (Question 8), availability (Question 9) and use of specialist resources (Question 10). For the second aim, two open-ended questions from section two were used to illicit psychologists' views on barriers and suggestions to overcome barriers to best practice implementation for individuals with dual disabilities.

Procedure

Following institutional ethics approval, recruitment for the online survey occurred through a number of professional networks Australia-wide using the Qualtrics platform.

Data Analysis

Descriptive statistics were used to examine psychologists' clinical practices when working with adults with ID and mental health disorders (aim one). One-way analyses of variance and chi-square analyses were used to examine work setting differences. Open-ended questions focusing on identified barriers to EBP and suggestions to overcome barriers to EBP were used to evaluate the second aim. Qualitative responses from these two questions were analysed by the first author using thematic analysis and prioritised according to how frequently the themes emerged. Following this, generated themes were reviewed by the second author for relevancy and consistency. Inter-rater reliability was established with 20% of qualitative responses from both open ended questions with an independent external rater with clinical psychology qualifications (Mean Cohen's Kappa = 0.80, ranging from 0.61 to 1; Mean Cohen's Kappa = 0.72, ranging from 0.54 to 0.88 respectively). For aim

one, themes generated from the question assessing identified special considerations made to mainstream practice also yielded adequate inter-rater reliability (Mean Cohen's Kappa = 0.73, ranging from 0 to 1).

Results

Aim One: Current Assessment Practices

As noted, 61 psychologists reported conducting mental health assessments with adults with ID. Eighty percent ($n = 49$) reported mental health diagnoses were made within their current work setting; and approximately one-third (35%, $n = 17$) reported that a psychiatrist was most likely to make a diagnosis of a mental health disorder for an adult with ID in their current work setting, whilst 25% reported that a psychologist ($n = 12$) was most likely to make this diagnosis. Only 8% ($n = 4$) reported clinical psychologists made mental health diagnoses in their workplace, while 12% ($n = 6$) reported diagnoses occurred in collaboration between a generalist psychologist and a psychiatrist. No differences in the diagnosing professional was found between government, non-government organisations (NGOs) and private practice settings, $\chi^2(10, n = 42) = 10.32, p > .05$. Collaboration between a clinical psychologist and a psychiatrist ($n = 1$) were rated as least likely when it came to making mental health diagnoses. The remaining 18% ($n = 9$) reported other professionals made mental health diagnoses within their work place. Eighteen percent of psychologists ($n = 11$) who reported conducting direct mental health assessments stated mental health diagnoses were not made within their current workplace/team.

When asked which professionals were they most likely to collaborate with during mental health assessments, psychiatrists were the most likely professionals (91%, $n = 51$) followed by behaviour support practitioners (89%, $n = 50$), general practitioners (GPs) (83%, $n = 46$) and other psychologists (80%, $n = 45$). In fact, 52% ($n = 29$) of psychologists surveyed who conducted direct assessments for people with ID reported collaborating with

at least four professionals on average. No differences in collaborations with GPs, $F(2,45) = .57$, $p > .05$; psychiatrists, $F(2,46) = 2.87$, $p > .05$; psychologists, $F(2, 46) = .95$, $p > .05$; behaviour support practitioners, $F(2, 46) = .14$, $p > .05$; and other professionals, $F(2, 46) = .15$, $p > .05$, were found between work place settings.

Psychologists ($n = 56$) were also asked what methods were used within their mental health assessments for adults with ID by nominating from a list of assessment methodologies, as well as nominating other methodologies not listed. A wide range of assessment tools and methods in the assessment process were reported. Almost all psychologists reported typically using at least four assessment methods (98%, $n = 55$). Clinical interviews, behavioural data, checklists/rating scales, direct observations, and functional analysis of behaviour were all reported as common assessment methodologies utilised. Semi-structured and full clinical interview schedules were less commonly utilised. See Table 2 for details.

Psychologists were further asked to indicate awareness, availability and use of specialist resources from a prescribed list using a multiple response format. Specialist assessment rating scales were reported to be commonly used during mental health assessments. When asked about awareness of specialised assessment resources, 93% ($n = 57$) rated some awareness of any specialised resources. A majority reported awareness of a minimum of three specialised resources (76%, $n = 42$). In terms of availability however, only 44% ($n = 24$) reported three or more of these resources were available in their workplace, while 27% ($n = 15$) reported no availability of resources. In terms of usage of specialised resources, 16% ($n = 9$) declared no use while 58% ($n = 32$) reported using at least three different specialist resources. No differences in awareness, $\chi^2(2, n = 48) = 3.45$, $p > .05$; availability, $\chi^2(2, n = 48) = .83$, $p > .05$; and usage of specialised resources, $\chi^2(2, n = 48) = 3.41$, $p > .05$, were found between psychologists across work settings.

Psychologists were further asked to nominate from a list of seven types of special considerations and modifications of mainstream clinical practice adapted for adult clients with ID whether these were applied to their current practice (See Table 2). They were also invited to elaborate and describe other types of special considerations not outlined in the list provided. Almost three-quarters of the sample (74%, $n = 40$) reported utilising six or more special considerations/modifications in their clinical approach when working with adults with ID. Psychologists stated within each special consideration category a variety of ways in which reasonable adjustments were made to suit the needs of individuals with ID and their families when conducting mental health assessments (See Table 2).

Table 2

Use of Specific Assessment Methodology and Special Considerations (N = 56)

Percentage Reporting use of Specific Assessment Methodology	Percentage	<i>n</i>
Clinical interview with family/carers	96.4	54
Behavioural data completed by carers/staff	89.3	50
Clinical interview with client	89.3	50
Checklists/rating scales	87.5	49
Percentage Reporting use of Specific Assessment Methodology	Percentage	<i>n</i>
Direct observation of client in interview setting	85.7	48
Functional analysis of behaviour	83.9	47
Direct observation of client in settings outside of the interview setting	82.1	46
Specialised assessment tools/rating scales	78.6	44
Semi-structured clinical interview schedules	53.6	30
Structured clinical interview schedules	37.5	21

Special Considerations Applied by Psychologists to People with ID	Percentage	<i>n</i>
Interview style (Flexible style, augmentative communication aides, avoid leading questions, interview carers if client non-verbal, adapt to level of ID of client, simplify language, check client understanding, support person)	89.3	50
Duration of sessions (Shorter but more sessions, level of ID dependent, flexible duration and number of sessions, longer sessions with breaks, rescheduling due to compliance issues)	85.7	48
Type and variety of informants (Anybody, carers/family, Paid staff, other informants)	85.7	48
Communication with my client (Use of devices, augmentative communication aides, modifying verbal language and awareness of seating layout)	82.1	46
History taking of the client (Comprehensive, access files, interview carers, look at behavioural data, clinical interview, more sessions with client to get history, developmental history, functional history, together with client and support worker, access files and previous assessments, baseline presentation, behavioural change to baseline)	82.1	46
The interview setting (Home, comfortable for client, wheelchair accessible, consider sensory sensitivities, adapt for privacy, clinic/office, offsite, client's choice, client's support settings, where client feels safe, flexible, less formal, easy to access for client)	78.6	44
Environmental considerations (Reduce distractions, in client's familiar setting, reduce distractions and distress of client, safe environment, calm environment, physically accessible setting)	75.0	42
Other special considerations (Take time to build rapport with client and in initial meeting, mindful of more sessions needed)	14.3	8

Aim Two: Barriers and Suggestions for EBP

Participants were asked to complete a separate multiple response question as to the reason specialist tools and resources were not available in the current workplace. Based on

the sub-sample of 61 psychologists, the most common reasons reported by psychologists across work settings were a lack of awareness of availability (48%; $n = 29$) and lack of funding (46%, $n = 28$). Lack of support from management was reported by 18% ($n = 11$) while time constraints within the assessment phase was reported by 16% ($n = 10$). A small proportion (11%, $n = 7$) of psychologists also reported mainstream resources (normed for the general population) as sufficient for use with individuals with ID.

Finally, the full sample of 102 psychologists was used to examine the open-ended questions pertaining to barriers to implementing best practice. When asked whether there were workplace barriers to best practice implementation when assessing mental health concerns in people with ID, 67% ($n = 69$) reported experiencing barriers while 32% ($n = 33$) reported no barriers. Participants who reported experiencing barriers were asked to elaborate in an open ended question. Four main themes and 27 subthemes generated from qualitative analysis emerged from open ended responses. Table 3 lists these themes and subthemes and their reported frequencies. Barriers identified most frequently included diagnostic difficulties, in particular, diagnostic overshadowing of mainstream mental health services, difficulties in accessing specialised assessment tools, access difficulties to mainstream mental health services experienced by adults with ID, and under resourced services including financial limitations. Collaboration difficulties between disability and mental health services and a lack of appropriate specialist mental health training and systemic and organisation issues were also highlighted as common barriers. Psychologists in government disability agencies reported diagnostic concerns, systemic/organisational issues, under resourced services, difficulties accessing specialist assessment tools, limited training available and collaboration difficulties with mainstream health services as the biggest barriers to EBP. NGO psychologists reported the inappropriateness of mainstream mental health services in servicing individuals with ID as the biggest barrier, while private practice

psychologists reported diagnostic issues and under resourced services as their greatest barriers.

When invited to provide suggestions on ways to overcome barriers to best practice, three main themes and 28 subthemes were generated from open ended responses (See Table 3). Suggestions included creating better links, communication and collaborations between disability and mainstream mental health services, improving access and affordability of training, improving access to specialist psychiatrists and/or specialist services, increasing government funding and increasing training and education in ID and mental ill health in particular via interagency training and supervision.

Table 3

Barriers and Suggestions Regarding Evidence Based Practice Implementation

Barriers to Evidence based Practice: Themes Generated ($n = 68$)	Number of times reported
Diagnostic issues	19
Access to resources	
Specialised assessment tools	10
High costs	1
Limited specialist psychiatrists	5
Mainstream tools inappropriate for intellectual disability population	2
Limited access to experts	3
Access to MH services	
Limited due to lack of specialist services	4
Difficulty accessing mainstream MH services	13
Under resourced services (including funding)	16
Costs to clients	2
Inappropriateness of mainstream MH services	8
Awareness of resources	
Unsure which tools are best practice	1
Specialist assessment tools	3

Barriers to Evidence based Practice: Themes Generated (<i>n</i> = 68)	Number of times reported
Availability of resources	
Time constraints	7
Intensity of caseloads/large case load	3
Limited availability of quality supervision	2
Limited training available	12
Systemic/organisation issues	11
Professional role limitations	5
Lack of training to GPs, psychiatrists in ID	3
Limited collaboration between disability and health	11
Poor communication between mental health professionals	1
MH and ID not core business in current role	3
Other	
Data collection difficulties with carers	1
Staff qualifications	5
Lack of research in assessment and treatment in ID	2
Personal perception of confidence	1
Limited by rural area	1
Suggestions to Overcome Barriers to Evidence Based Practice: Themes Generated (<i>n</i> = 64)	
Training	6
Mandatory training	3
Research updates/advances	3
Improve access and affordability	7
Training in MH diagnosis	2
Training in assessment resources	2
To support workers	3
Train psychiatrists in ID	5
Change understanding of MH and challenging behaviour dichotomy	3
Online	2
Supervision/consultation	3
Experts to disseminate information on best practice	3

Barriers to Evidence based Practice: Themes Generated (<i>n</i> = 68)	Number of times reported
Interagency collaborations	
Better links and communication between disability and health	17
Interagency training and supervision	6
Joint placements	1
Access to resources	4
List of specialist psychiatrists/specialist services	11
Rural services	2
Reduce costs of assessment tools	1
Increase funding from Government /Medicare	9
Reduce training costs	1
Involve GPs	1
Educate work setting on benefits of professional development	2
Other	
Research to develop assessment measures	2
Engage with NDIS	1
Support families	3
Practice/leadership groups	2
Organisation to support person holistically	1
Increase workforce size	1
Further education	7

Discussion

The findings from this study indicate that overall, Australian psychologists working primarily with individuals with ID are generally aware of best practice standards in ID and reported implementing a number of clinical assessment practices consistent with current best practice guidelines. However, numerous barriers have been reported in an attempt to integrate best practice standards into practice.

The first aim was to explore whether current assessment practices of psychologists were in line with available national and international guidelines for best practice. The findings indicated that on the whole, psychologists' clinical assessment practices when providing a mental health service to adults with ID were aligned with currently available best practice guidelines (e.g. Deb et al., 2001; Department of Developmental Disability Neuropsychiatry, 2014). Psychiatrists were reported as the most likely to provide a mental disorder diagnosis, although the percentage was relatively low. This is consistent with previous findings on a survey with Australian psychiatrists which revealed limited confidence in mental health diagnoses with individuals with ID (Edwards et al., 2007). The very low percentage of participants reporting clinical psychologists as the most likely profession to diagnose may be a reflection of the smaller proportion of clinical psychologists working in the ID field in comparison with generalist and provisional psychologists. However, multi-disciplinary collaboration appears to be standard practice as reported by the majority of participating psychologists. This is consistent with the recommendations of current Australian and international guidelines (Department of Developmental Disability Neuropsychiatry, 2014; NICE, 2016).

When participants were asked what assessment methods formed part of a typical mental health assessment when working with clients with ID, reported methodology did not differ from typical behavioural assessment methodology used in mainstream practice. This consisted of clinical interviews with family/carers and the client, collecting behavioural data, checklists/rating scales, direct client observations and conducting behavioural functional assessments. Notably, almost all psychologists reported using at least four assessment methods during a typical mental health assessment which suggests the complex nature of assessing an individual with ID for mental health concerns. The use of multi-method approaches is in line with current best practice recommendations (e.g. Deb et al., 2001). It is not surprising that structured clinical interview schedules were the least commonly utilised

methods given the additional time requirements, which raise feasibility issues in regular clinical practice, as well as the scarcity of these resources designed for the ID population.

Most psychologists reported some awareness related to the availability and use of a range of specialist assessment tools. However, a third of psychologists reported such tools were unavailable to them within their workplace. It was however encouraging that more than half the sample used at least three specialist resources within their assessments, consistent with best practice guideline recommendations to use specialist resources when assessing mental health in people with ID (e.g., Deb et al., 2001; Department of Developmental Disability Neuropsychiatry, 2014; NICE, 2016). Workplace resource limitations and lack of awareness were nominated as the biggest barriers to access. Given these findings, it is clear that more needs to be done to build awareness of specialist resources and to educate clinicians and managers within the workplace on their roles in mental health assessment for people with ID to ensure practices can be in line with EBP.

It is widely acknowledged in the literature that reasonable adjustments to mainstream practice are required in order to meet the needs of individuals with ID and their families (e.g., Department of Developmental Disability Neuropsychiatry, 2014; Turner and Robinson, 2011). In the current study, psychologists were found to utilise a variety of special considerations when providing mental health services to adults with ID, which are consistent with best practice recommendations. Considering that the majority of the sample came from disability services, such reasonable adjustments would be expected in such services given the emphasis on person centred practices.

In evaluating aim two of the study, a number of barriers to EBP implementation were revealed. Diagnostic issues including diagnostic overshadowing by mainstream mental health services and collaboration challenges between disability and health sectors were considered the biggest barriers overall, and which further impacted on access to mainstream

mental health services. In Australia, despite the introduction of the Memorandum of Understanding in NSW (NSW Department of Health, 2010), collaboration difficulties between disability and mental health services continue to present as barriers, as did a lack of appropriate specialist mental health training. The frequent highlighting of diagnostic overshadowing evidenced in current services also warrants a system-wide acknowledgement of the high rates of co-morbidity of mental health problems in people with ID and accommodation to the needs of individuals with ID and their families. These findings highlight the need for national interagency roll out of training between disability and health services to ensure services are meeting EBP standards supported from the top down. In fact, interagency training between health and disability sectors has previously been highlighted as a necessity in Australia (e.g. Lennox & Chaplin, 1996), and a model of training has been trialled by Mohr and colleagues (2002). Evaluations from this training found increases in participants' confidence and knowledge in dual disabilities and an ongoing commitment to change clinical practices and educate others within the workplace (Mohr et al., 2002).

Specialist services for individuals with ID and co-morbid mental health disorders exist in the UK and to a lesser extent in certain states in Australia. A shortage of specialised services was also noted as a barrier by psychologists, perhaps implying the inadequacy of current mainstream services in catering to the needs of individuals with ID. Suggestions made by participating psychologists on ways to overcome identified barriers to EBP included interagency training and improving communication and collaboration between health and disability services which are outlined in a number of recent Australian practice guidelines and policies (e.g., Department of Developmental Disability Neuropsychiatry, 2014, 2016), yet are rarely implemented in practice. Given the ongoing reported difficulties in collaboration between health and disability services, interagency/inter-departmental training across all tiers and sectors of health and disability services, and ongoing

commitment to improving clinical competency in working with individuals with ID and co-morbid mental health concerns will assist better mental health outcomes in this population.

Study Strengths, Limitations and Implications

This study is the first to address specific assessment practices of psychologists working in the field of ID and co-morbid mental health disorders. To our knowledge, no studies have yet to compare current practices with evidence based benchmarks in the field of ID. The current findings highlight a range of specific practice barriers in implementation of EBP when working with adults with ID. However, the findings need to also be considered in context of several limitations, first, the initial aim of this study was based on a very modest sample size ($N = 61$). Second, the survey did not capture information on the composition of disciplines within psychologists' work settings. This may have affected diagnostic and collaboration practices as psychologists working within multi-disciplinary teams would generally have more access to multi-disciplinary collaboration, and diagnostic roles may be more clearly defined as a result. Third, there was a lack of representation from psychologists in mainstream mental health settings. Future research could explore if clinical practices and values on best practice for individuals with ID differ in this group of psychologists to inform training and development needs of psychologists from a variety of work settings. However, it was beyond the scope of the study to explore the impact of the larger workplace system on implementation of best practice in ID. Potential systemic differences and impact on clinical practice for psychologists working in dual disabilities warrants further investigation.

In conclusion, the findings from this study suggest psychologists working with people with ID and co-morbid mental health disorders are generally cognisant of what constitutes best practice, yet experience practical barriers with implementation of some components in line with current best practice recommendations (e.g., Department of

Developmental Disability Neuropsychiatry, 2016; NICE, 2016). In Australia, collaboration between health and disability services, diagnostic complications and under resourcing are barriers experienced by a majority of psychologists that continue to compromise access to quality mental health care for individuals with ID and co-morbid mental health concerns. To ensure Australian practice is on par with international best practice standards, system-wide support is needed to provide better governance of best practice and promote interagency collaboration. Leadership at high levels of the system are pivotal to serve as role models for effective collaboration and to promote high standards of excellence in working with people with ID. Together with ongoing interagency professional development in a variety of areas relating to mental health and ID, this will ensure that individuals with ID and co-morbid mental health concerns do not continue to fall through service gaps.

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Bridging Chapter end of Phase One

The aim of the second paper from the initial phase of this research was to investigate specific clinical practices of Australian psychologists who conduct mental health assessments with adults with dual disabilities and workplace barriers to evidence based practice implementation. Findings revealed that psychologists who conducted mental health assessments with adults with an intellectual disability as part of their role reported a number of practices that aligned with current national and international practice guidelines. Given the finding from the first paper from this study (Chapter 2) where only 49% of psychologists surveyed reported specialist expertise in dual disabilities, this latter finding is encouraging. Despite the limitations in evidence based practice, participating psychologists in this initial study demonstrated at least self-reported awareness of general best practice principles such as inter disciplinary and agency collaboration, application of reasonable adjustments to mainstream practice to suit the needs of individuals with an intellectual disability and their families, use of specialist assessment tools normed for the intellectual disability population, and referring on to specialist services when required. Due to the limitations of this initial phase of this study, (as outlined in Chapters 2 and 3), such practices can only be understood in isolation. What remains unknown is the process of mental health assessment and how the above clinical assessment practices are integrated and understood within the context of the clinician's practice. To this end, the objective of the second phase of this program of research was to address this issue. Specifically, the aim of the second study was to investigate in more detail the views and reported practices of psychologists working in dual disabilities using focus group methodology.

Furthermore, consistent with findings from the initial paper (Chapter 2), the findings from Chapter 3 suggest that psychologists held limited confidence in mental health disorder diagnosis and often saw this as the role of psychiatrists given the high rate of referrals to

psychiatrists by psychologists for mental health diagnosis. Given the limited number of psychiatrists specialising in intellectual disability available in Australia, this raises concerns over the sensitivity and specificity of such mental health assessments. A number of workplace barriers to evidence based practice implementation were also reported by psychologists in this initial study. However, it was beyond the scope of this first study to examine in detail how such barriers interact and influence psychologists' clinical practices within the context of their workplace and the wider service system. Accordingly, this was one of the objectives of the second phase of this program of research where psychologists were invited to discuss facilitators and barriers to evidence based practice experienced within their work settings.

In summation, the findings from this initial phase provide an overview of the perceptions and clinical practices of Australian psychologists who work with individuals with an intellectual disability. For the next phase, the aim was to investigate in more detail the clinical practices of psychologists working primarily with individuals with an intellectual disability via qualitative methods. Separate focus groups with psychologists from government and non-government disability organisations enabled exploration of workplace factors impacting on evidence based practice implementation. There were two specific aims for this second study which are presented in two further papers (Chapters 4 and 5). In particular, the aim of Chapter four was to investigate clinical practices of Australian psychologists and its alignment with national and international best practice standards and their adaptations to limits in evidence base in dual disabilities in their everyday practice. The aim of the Chapter five was to explore the adherence to current national and international best practice standards by Australian psychologists working primarily with the intellectual disability population and facilitators and barriers to evidence based practice implementation.

Chapter 4: Phase Two Paper One

Best Practice Principles when Working with Individuals with Intellectual Disabilities and Co-morbid Mental Health Concerns

Joyce Man & Maria Kangas³

Centre for Emotional Health, Macquarie University, Australia

* Manuscript submitted

³ This is to confirm Joyce Man is the first author and has completed all field work, primary coding and data analysis and the first full draft of this paper.

Abstract

Background: Working with individuals with dual disabilities can be a complex process in the presence of limited evidence base to guide clinical practice. This qualitative study aimed to investigate perceptions of best practices of Australian psychologists working with this specialist population.

Method: Thirty eight Australian psychologists working in the intellectual disability field participated in eight semi-structured focus groups. Perceptions of evidence-based practice for individuals with an intellectual disability and in relation to mental health assessment were explored in the context of limited available evidence base.

Results: Psychologists demonstrated resourcefulness in adapting to limits in evidence based practice and making adjustments to mainstream practice to suit the needs of individuals with dual disabilities. Findings suggested the necessity of practice based evidence in contributing to the evidence base to guide clinical practice.

Conclusions: Implications for strengthening clinical competency in mental health assessment and bridging the research and practice gap are discussed.

Keywords

Disability, health, intellectual, mental, practice

Introduction

Psychologists are trained as scientist practitioners where evidence based practice (EBP) which is considered ‘the integration of best available research with clinical expertise and client characteristics, culture, and preferences’ (APA Presidential Task Force, 2006) is the clinical practice gold standard (Australian Psychological Society, 2006, p. 273). At present, a variety of practice guidelines are well established for the mainstream population; for example clinical practice guidelines for treatment of Obsessive Compulsive Disorders (National Institute for Health and Clinical Excellence, 2005). Despite the availability of such guidelines, adherence is variable.

In regards to EBP adherence in the mainstream literature, a US survey conducted with mental health providers from community children's mental health services found that only 16% of interventions ($n = 41$) were provided with full integrity to evidence based treatment protocols, while 24% of interventions ($n = 59$) were never or almost never provided using the full treatment protocol (DiMeo, Moore & Lichtenstein, 2012). Another US qualitative study with practising psychologists found that many were open to use of treatment protocols if this allowed for adaptations to be made to suit the needs of complex client presentations (Stewart, Dirman, Chambless, 2012). Psychologists from this study reported using an eclectic approach to their clinical work and held some misgivings around empirically supported treatment protocols, criticising it as ignoring the individuality of the client (Stewart et al., 2012). In relation to the above studies, the nature of client presentations is unknown therefore making it difficult to ascertain whether clinicians were tailoring their interventions to suit unique client presentations. As a result, it is unclear whether adaptations to EBP practice were driven by client characteristics such as diagnostic complexity or clinician factors such as clinical experience and expertise. What is known however is that adaptations to EBP by psychologists are not uncommon.

Stewart and colleagues (2012) suggest that psychologists' high regard for clinical judgment and expertise created considerable barriers to the adoption of evidence based treatments. On the contrary, emphasis on clinical expertise can also be considered an important requirement in order to successfully adapt EBP (McGrew, Ruble & Smith, 2016). Clinical expertise integrates client characteristics which include diagnostic complexity or co-morbidities with cultural factors in order to maximise outcomes of intervention (McGrew et al., 2016). Despite compromising the fidelity of EBP protocols, flexibility of therapists in their implementation of the EBP by taking into consideration client and cultural factors is seen as vital (Jensen-Doss, 2009; Woolf, 2008). A systematic review of studies on psychological treatments for depression with culturally diverse populations found that two thirds of the studies reported cultural adaptations to psychological treatments for depression, and that their efficacy was comparable to standard psychological interventions (Chowdhary et al., 2014). Given the value in adaptations to mainstream EBP practice, investigations regarding adaptations to mainstream practice in the intellectual field will assist to inform whether adaptations add clinical value.

In the field of intellectual disability there is a general consensus that mainstream EBP for mental health disorders are not always directly applicable, hence, adaptations to mainstream practice are similarly required (Ali et al., 2013). In particular, where research evidence and national guidelines are lacking or inaccessible, clinicians may draw on a combination of available research literature and expert opinion in accordance with their clinical experience and professional training. Given the above findings in the mainstream literature regarding adaptations of EBP; implementing EBP in the area of intellectual disabilities may involve even more emphasis on clinical judgment and expertise to compensate for the limited research base. In support of this, current international guidelines on service delivery for individuals with an intellectual disability advocate for person centred practices that accommodate the needs of individuals with an intellectual disability (e.g.

Department of Developmental Disability, 2014). In the UK, in order to maximise accessibility of mainstream health services to individuals with an intellectual disability and their families, reasonable adjustments to mainstream practices are a legal requirement (Hoole & Morgan, 2011). In a more recent Australian national study (Man, Kangas, Trollor & Sweller, 2016b) [*Chapter 3 of Dissertation*]; psychologists reported applying special considerations when assessing a client with an intellectual disability. Half of participating psychologists who conducted direct assessments of mental health in adults with an intellectual disability reported modifying at least seven areas of practices when conducting sessions with their clients. Common areas of adjustments included communication style, interview setting, interview style and duration of sessions. A recent UK study (MacArthur et al., 2015) investigated the role of learning disability liaison nurses in facilitating reasonable adjustments in hospital settings. Reasonable adjustments in the areas of access to information, adjustments to care, environment of care, equitable care, identification and meeting of patients need, and use of specialist tools/resources were most commonly made by learning disability liaison nurses (MacArthur et al., 2015). Such findings demonstrate that reasonable adjustments and adaptations to mainstream practice are common and necessary in the intellectual disability population, however further investigation into how reasonable adjustments should be operationalised in accordance with available international best practice standards is required.

International and national guidelines for best practice in intellectual disabilities typically describe a systemic, trans-disciplinary and collaborative approach to service delivery for individuals with an intellectual disability (e.g., Department of Developmental Disability Neuropsychiatry, 2014; National Institute for Health and Clinical Excellence, 2016). To this end, in a recent Australian national survey of psychologists working with adults with an intellectual disability, inter-disciplinary collaboration was reported as standard practice during mental health assessments (Man et al., 2016b) [*Chapter 3 of dissertation*]. A

large majority of psychologists surveyed in this Australian study also reported awareness of a range of specialist assessment tools and resources but not necessarily availability of these resources within their work settings (Man, Kangas, Trollor & Sweller, 2016a) [*Chapter 2 of Dissertation*]. This suggests psychologists working with individuals with an intellectual disability report some practices that are congruent with current best practice recommendations particularly in relation to inter-disciplinary and inter-agency collaboration.

Furthermore, an Australian study utilising a linkage database in New South Wales found that people with an intellectual disability are more likely to receive ambulatory mental health treatment for more severe mental health disorders, and had more contact with mental health services compared with people without intellectual disabilities (Howlett, Florio, Xu, & Trollor, 2015). Similar findings were found in a review of UK hospital experiences of people with an intellectual disability (Iacono, Bigby, Unsworth, Douglas & Fitzpatrick, 2014). This lends support for the view that people with an intellectual disability present with additional complexity in their service needs compared with individuals presenting solely with a mental health diagnosis (Howlett et al., 2015).

What remains unknown is how such clinical practices for individuals with an intellectual disability and co-morbid mental health concerns (dual disabilities) compare with current practice guidelines. Further investigation is needed regarding psychologists' perceptions of EBP and how special considerations are integrated into best practice for individuals with an intellectual disability given the lack of well disseminated and endorsed national guidelines. Particularly in the area of mental health assessment in intellectual disabilities, a paucity of research exists which examine current clinical practices and whether they differ from mainstream assessment practices given the specific needs of this specialist population. Given the role of clinical expertise in identifying reasonable adjustments to suit

the needs of the individual with an intellectual disability, how this expertise plays a role in best practice in intellectual disabilities has yet to be understood.

At present, EBP research typically involves establishing benchmarks of practice for a group of individuals sharing a single diagnosis (American Psychiatric Association, 2006). One common criticism of this is the neglect of individual factors and co-morbidities of presenting problems. As highlighted in the intellectual disability population, heterogeneity and co-morbidity are common and often warrant modifications to mainstream evidence based practice. As a result, this lends itself to practice-based evidence where clinicians contribute to the knowledge base via assessment, intervention and ongoing monitoring of the course of their clinical practice (Kratochwill et al., 2012). It would be important to explore where practice based evidence plays a role in the day to day operations of practicing psychologists and particular in relation to implementation of available EBP in intellectual disabilities. This may have implications for how EBP is implemented and its growth in the intellectual disability field, as well as in improving future training of psychologists working in this field.

In addition to client and clinician factors, organisational factors may also impact on EBP implementation. For instance, lack of agency resources; unsupportive organisational culture; research environment; and inadequate supervision have been found to create barriers to EBO implementation (Gray, Joy, Plath, & Webb, 2013). In the context of intellectual disability and comorbid mental health, the organisation has also been reported to impact on certain clinical practices where differences were found between psychologists from private practice, non-government organisations and government disability services in their perception of adequacy of resources to assess and diagnose mental health disorders in individuals with an intellectual disability in their work settings (Man, Kangas, Trollor & Sweller, 2016) [*Chapter 2 of thesis*]. Given these findings, an exploration of views on best

practice in the context of psychologists' work setting would allow for exploration of organisational factors impacting on EBP.

Aims of Current Study

The aim of this study was to investigate the views of Australian psychologists on how best practice should be implemented for individuals with an intellectual disability and co-morbid mental health concerns in relation to their clinical practice. This was explored within the context of the psychologists' workplace in either government or non-government disability organisations.

Method

Participant Characteristics

Thirty eight psychologists (8 males, 30 females) in New South Wales, Australia participated in a total of eight focus groups. Twenty participants worked in government disability organisations while 18 were from non-government organisations. Overall, 66% of participating psychologists held undergraduate psychology degrees while 34% held postgraduate psychology qualifications. Years of experience registered as a psychologist ranged from one to 36 years ($M = 13.5$, $SD = 9.3$), while years of experience in intellectual disabilities ranged from two to 30 years ($M = 14.5$, $SD = 8.6$). Years in current role was similarly variable ranging from one to 29 years ($M = 7.7$, $SD = 6.5$). Psychologists held varying proportions of caseloads with clients with co-morbid intellectual disabilities and mental health concerns ranging from 5 to 100% ($M = 65\%$, $SD = 26.2$). Two-thirds of participants (68%; $n = 26$) were employed as psychologists while 18% were employed as behavior support specialists ($n = 7$). The remaining 14% held other roles ($n = 5$) such as management roles.

Measures

Psychologists completed demographic items on academic training, current and previous work settings, years of experience, nature of current role, proportion of caseloads with dual disabilities, and training and use in a variety of treatment modalities. Semi-structured focus groups with psychologists in the same work setting were conducted as part of a larger study [*i.e., comprising the second phase of this PhD program of research*]. Two focus group questions examined current understanding and perceptions of EBPs for individuals with an intellectual disability and in relation to mental health assessment for individuals with an intellectual disability. A third focus group question explored what clinicians drew upon when evidence base was limited. See appendix B, p. 134 for a list of focus group questions used.

Procedure

Following institutional ethics approval, clinical and generalist psychologists who worked with adults with an intellectual disability in Australia with a minimum of two years of registration were targeted for recruitment. A qualitative methodology was chosen to enable a detailed exploration of psychologists' views on best practice working with people with dual disabilities. Focus group methodology was chosen to better allow for work setting comparisons to be made between government and non-government disability organisations. Providing opportunities for participating psychologists to reflect on their clinical practice in the presence of peers within the same work setting may prime them to answer the research questions within context of their current work setting. This contrasts with existing qualitative studies involving individual interviews with psychologists investigating their views on EBP which do not explore work setting influences (e.g. Stewart et al., 2012). Eight focus groups consisting of three to six psychologists in each group were conducted with four government disability agencies and four non-government disability agencies in their

corresponding work settings. Following completion of the demographics questionnaire, participants engaged in a semi-structured focus group lasting for a maximum of two hours which was audio taped. Each focus group followed the same format where psychologists were asked three open questions as discussed in the previous section. A summary of the discussion arising from each focus group was provided at the conclusion to allow for clarification and further input.

Participants were recruited via a variety of formats which included advertising through the first author's professional networks and the interest groups of professional psychology organisations within New South Wales.

Data analysis

Audio taped focus groups were transcribed and qualitative analysis of each transcript was undertaken. Thematic analysis (Braun & Clarke, 2006) was used to identify themes arising from each of the three research questions. N Vivo software (version 10) was used to manage the coding process of all phases of the thematic analysis by the first author. Phase one involved generating initial codes for each of the three research questions upon familiarisation with the data (i.e., several readings of each of the focus group transcripts). Phase two involved sorting the initial codes and condensing them into preliminary themes based on similarity in meaning or category. Phase three comprised reviewing themes for further refinement. Refined themes were checked against all their collated extracts from their corresponding transcripts and in relation to the entire data set. This ensured themes generated reached saturation and were qualitatively different from each other. The fourth phase involved final refinement of themes and considering sub-themes in relation to one another as well as to ensure saturation of themes. Differences in emerging themes between psychologists from government and non-government settings were also explored. Themes

and sub-themes derived from phase three and four were reviewed by the co-author. Where discrepancies emerged, discussions ensued until consensus was reached.

Results

A total of four themes and ten sub-themes were generated in exploration of reported best practices in intellectual disabilities and co-morbid mental health by Australian psychologists. These themes were: Assessment and formulation, Systemic approach to intellectual disability care, Clinical reflections, and Informing clinical practice. See Table 1 for a full list of themes and sub-themes.

Table 1

Emerging Themes and Subthemes

Themes	Subthemes
Assessment and formulation	Assessment tools
	Holistic approach and differential diagnosis
Systemic approach to intellectual disability care	Person centred care
	Collaboration
	Psycho-education
Clinical reflections	Clinical experience
	Clinical role
Informing clinical practice	Legislation and professional guidelines
	Evidence based practice
	Professional development

1. Assessment and Formulation

Two sub-themes emerged in relation to processes involved in conducting mental health assessments with individuals with an intellectual disability.

Holistic assessment including differential diagnosis.

Participants across government and non-government (NGO) work settings reported a range of factors including environmental, systemic and medical influences during mental health assessments with individuals with an intellectual disability. Psychologists recognised the complexity of this client group and noted taking into account differential diagnoses, and being sensitive in distinguishing mental health symptomatology from challenging behaviour presentations within case formulation.

I think we're pretty good at delineating presentation, into ID or mental health, and there's still development (Focus group 7, NGO)

I think we always look for a differential diagnosis. I think that in terms of our population group we are really aware that there is a high percentage of people with co-morbid mental health issues. It's always there in terms of our assessment process.

(Focus group 2, Government)

In practice, holistic assessment involved liaising with multiple informants and stakeholders across multiple environments and being cognisant of a range of possible underlying causes for the individual's presentation.

We're actually approaching it with a developmental point of view and actually looking at the neurodevelopmental pathways of this young person and therefore this is why we have these behaviours and this is how we need to treat them (Focus group 6, NGO)

When you're trying to work towards eliminating learnt behaviour as a possible function, I think observation's critical across the environments (Focus group 1, Government)

Assessment also involved applying special considerations and adaptations to mainstream assessment practice.

A lot more pre-assessment. Do they understand the difference between self-talk and auditory delusions with their imaginary thinking. (Focus group 7, NGO)

Always going back and grabbing the history of what happened to that client before, when was the first diagnosis given, what were the circumstances around that time as well, because we'll often have clients that we diagnosed around times when other things happened for them. (Focus group 1, Government)

Assessment tools.

The second subset of themes which emerged in relation to the assessment and formulation theme related to Assessment tools. Psychologists described application of both mainstream and specialised assessment tools with individuals with an intellectual disability. A number of assessment resources specific to the intellectual disability population were noted such as the Diagnostic Manual-Intellectual Disability (DM-ID) (Fletcher, Loschen, Stavrakaki, & First, 2000), Developmental Behaviour Checklist (Einfeld & Tonge, 1995) and Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Moss et al., 1998).

Using multiple resources as well. So you may use the DBC or other tools e.g. PAS-ADD, so not just relying on one measure. (Focus group 3, Government).

When specialist assessment resources were unavailable, adaptations to mainstream assessment resources were also noted.

I use a lot of visuals even with DASS (Depression, Anxiety and Stress Scale) the actual rating scale from 0 to 3 I have a little laminated card that has the numbers... so every time I ask a question I refer to it and I ask the client to point rather than trying to conceptualise what frequently means. (Focus group 5, NGO)

I use the ACE-Scale and I use that mainly to provide proven documentation that the client did actually go through what that is a high chance that they went through very traumatic experiences as a child. (Focus group 3, Government)

Some limitations to mainstream resources such as the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria (American Psychiatric Association, 2013) were also noted.

We obviously use DSM but then again, I think, once you get below a (person with) mild, moderate intellectual disability, (for) those, the DSM criteria are probably not really valid for that group. You wouldn't use DSM criteria to diagnose depression in someone with a severe intellectual disability because I don't think the picture would look the same. (Focus group 8, NGO)

2. Systemic Approach to Intellectual Disability Care

The second theme which emerged related to working within a system of supports for the individual with intellectual disability. Three sub-themes emerged from this theme.

Person centered care.

The first sub-theme involved taking into account idiosyncratic factors when providing intervention and/or support. This was common amongst both government and non-government psychologists.

I was talking to a clinician yesterday and he was saying I'm having to explain to group home staff (who are) saying that he leaves the house for no purpose, actually, well, don't you ever feel like you just want to get out of the house and go for a walk? Oh but he's psychotic; he's leaving the house for no purpose. No, he may well be psychotic but he's living with five people he doesn't like. (Focus group 4, Government)

I also put myself in the client's shoes, so I would say, I will how would I respond if I had XYZ, what would the outcome, how would I feel and so I kind of use that as a way of understanding the client at times. (Focus group 3, Government)

Given the complex needs of individuals with dual disabilities, making reasonable adjustments to mainstream practice also appeared to be standard practice for a majority of psychologists. Adjustments to communication style, extending the assessment process, allowing more time and assessing across a number of different environments were some of the ways in which mainstream practice was modified.

Paying attention to the non-verbal behaviour and that also means repeating information, making sure it's simpler, ascertaining whether it's understood and asking them for clarification. (Focus group 5, NGO)

We definitely make reasonable adjustments because it's just unreasonable to think that if we can work with a client and try to do general cognitive therapies. It has to be modified (e.g.) visuals. (Focus group 3, Government)

Collaboration.

The second sub-theme emerging from Systemic approach to intellectual disability care was working collaboratively with various professionals. In particular, working in partnership with a range of stakeholders was reported standard practice for psychologists. Psychologists across work settings reported collaborating with mental health clinicians, professionals from other services and disciplines, client and family and support systems. Engaging stakeholders such as school, parents, respite staff and other allied health and disability professionals was seen as necessary in bringing about the best outcomes for the client.

If you can have a meeting with the parents, the school, paediatrician, the liaison people, you're going to get the best outcome because we're going to the home and we're seeing what's happening at home and the school, and then operate upon it.

(Focus group 8, NGO)

Close collaborations between mainstream mental health and disability services was also reported.

So I think the implementations of we're talking about best practice, it's important that in those crucial stages there's negotiations about when these guys are going to get discharged. What are you guys going to be providing them in community and what's going to change for them in the community. (Focus group 1, Government)

However, many disability service psychologists reported experiencing barriers to collaborating effectively with mainstream mental health services. Operational differences between the disability and mental health sector were reported.

There's one client who's transitioning out of mental health services into residential setting and implementing best practice is about developing a relationship with the people in the hospital. That has been absolutely fundamental for this particular client and gratefully, I have a social worker who does have some understanding of the impact of trauma and who is able to then interpret our language into mental health language. There isn't a common language between intellectual disability and mental health. (Focus group 6, NGO)

Barriers relating to access to mental health services were reported more by government psychologists.

But it can sometimes be Health (services) may not have people with the right level of skill to be able to manage that case in a collaborative way with us. So it looks a lot like

they're just shutting the doorway and saying, it's your client to deal with. But it can be that they just don't have the expertise. (Focus group 1, Government)

Psycho-education.

Psycho-education was the third subtheme emerging under Systemic approach to intellectual disability care. Provision of training and psycho-education to stakeholders involved in the care of an individual with dual disabilities was reported across work settings.

It's not just education to Mental Health (services) we provide that to, it's whoever's surrounding the person. In terms of the system, we have to do the same education, because our Disability (service) staff don't understand mental health either, in the same way Health (service) staff don't understand disability. (Focus group 1, Government)

Carers reported training and education to carers as well as to staff working in both disability and mental health services was considered necessary.

It's really important to gain the carer's perspective and to educate them as well to look out for these changes in behaviour that might indicate that there's something more going on with that person (Focus group 7, NGO)

It's also helping the staff and families negotiate the mental health system. It's giving them psycho education about what they need to do to ensure that they're getting good service or getting any service from the mental health services, so that they're able to respond to crisis situations. (Focus group 2, Government)

3. Clinical Reflections

The third theme pertained to psychologists reflecting on their clinical practice when working with people with an intellectual disability. Two sub-themes emerged from this theme.

Clinical experience.

A majority of psychologists made reference to the first sub-theme- the role of clinical experience in guiding their work. Psychologists across the board reported drawing on their clinical experience in the absence of clear practice guidelines. Many noted a sense of clinical intuition, a ‘gut feeling’ built upon years of experience in the field. This was commonly drawn upon to compensate for a lack of evidence base to guide their work with individuals with dual disabilities.

So you start with a gut feeling and then you ask ‘What would my client be going through?’ and then you kind of lead into more sort of data searching. (Focus group 3, Government)

It’s ingrained in your profession, like suicide risk assessment, mental state exam.

You do all of that as you walk in (Focus group 6, NGO)

Clinical role.

The second sub-theme under Clinical reflections related to the role of the clinician. In particular, psychologists across work settings expressed limited confidence in mental health diagnosis

I struggle. I tend to look to the Doctors and Psychiatrist, Paediatricians for health with regards to what might be going on. (Focus group 3, Government)

Non-government psychologists also noted their role at times involved advocacy for their clients in order to access mental health services.

At times we might have an advocacy role as well, with mental health and ID, in the sense that there’s, maybe in some of the public systems, there’s a blur between, if

you have a client presenting with mental health issue and they're sort of saying that this is a disability issue. (Focus group 7, NGO)

Psychologists across work settings also viewed their role in mental health assessment as facilitating psychiatrists with data gathering and mental health screening.

I don't actually see my role as doing formal mental health assessments. However, I guess, certainly my role (is) around identifying where there might be something going on and helping people understand why they might be concerned I guess helping people who might make the diagnosis. (Focus group 6, NGO)

If I'm doing a client assessment and there are some mood issues I want to know whether (it) is due to intellectual impairment versus just mood difficulties. It is a screening tool, it's not a diagnostic tool. (Focus group 2, Government)

4. Informing Clinical Practice

The fourth and final theme: Informing clinical practice centred on the use of a range of sources to guide best practice. Three sub-themes emerged from this theme.

Legislation and professional guidelines.

The first sub-theme referred to workplace practice guidelines as well as national disability acts. For example, the Disability Inclusion Act 2014 (NSW Government, 2014) and the Memorandum of Understanding in New South Wales, Australia (NSW Department of Health, 2010) were mentioned as influential to clinical practice.

It is about following existing guidelines and incorporating the clinical practice with the disability legislation, the inclusion bill, disability act, there to ensure people receive the same service regardless of the fact they have an intellectual disability. (Focus group 5, NGO)

Other psychologists highlighted the need to ensure a sense of equity in service access and quality for clients with an intellectual disability. Non-government psychologists specifically mentioned developing or abiding by their organisation's specific models of best practice.

We've been fairly instrumental in helping some of the larger disability organisations actually define what their framework looks like. We're pushing really hard to develop best practice in our work by pulling from other fields (Focus group 6, NGO)

Drawing on professional and organisational models of care such as positive behaviour approaches was mentioned by both government and non-government psychologists. Actually there are quite a few networks, there's Psych DD, APS, interest group on research and development in intellectual disabilities. (Focus group 8, NGO)

Most psychologists in both government and non-government sectors also noted consulting with expert panels in dual disabilities.

We actively go out and seek out the people who have expertise in both- my example of the forensic discipline and working with people with ID. (Focus group 1, Government)

Professional development.

The second sub-theme under Informing clinical practice centred on professional development. Psychologists across work settings emphasised ongoing formal and informal professional development as crucial to delivering best practice. Some described a 'culture of learning' within the team/organisation and many actively shared information amongst colleagues in peer consultation settings and attended regular training.

Keeping up to date with new research and new information and sharing that amongst within the team which we have monthly supervisions where we do that. And we talk about new strategies and new practices that can be implemented that are consistent (Focus group 5, NGO)

I guess using each other's experience as well. Because we are working in an area where there's that lack of formal evidence base. (Focus group 1, Government)

Evidence based practice.

The third sub-theme involved consulting with both research in the intellectual disability field as well as adapting findings from mainstream literature when specialist literature was unavailable to inform the practitioner's work. Both government and non-government psychologists reported having some access to journal databases and professional guidelines to facilitate working with individuals with an intellectual disability.

Different times there have been people that have access to broad databases because they're studying or what have you, so they often use those. (Focus group 6, NGO)

Use PSYCinfo to do a search...hopefully there is some new research which has come out. (Focus group 1, Government)

In the absence of available evidence based practice, psychologists frequently noted utilising practice based evidence as a way to determine the efficacy of treatment programs as well as to increase the sensitivity and specificity of mental health assessment for individuals with an intellectual disability. Practice based evidence involved gathering case study support via the clinician's own practice in place of empirical literature during instances when such empirical evidence was lacking or limited. This also involved measuring outcomes in ascertaining the efficacy of adapted treatment programs.

If you do something new, you evaluate to make sure that it's actually working.
(Focus group 8, NGO)

Occasionally, I'll sort of incorporate like an ethical decision making model type thing into it. So what are the potential benefits of using something that's developed for the mainstream but not using anything at all or using something else. (Focus group 4, Government)

There was uniformity across work settings regarding clinicians' acknowledgement that their clinical work involved adaptation of mainstream practices or developing new ways of working with individuals with an intellectual disability. Adaptations were noted in a range of areas which included adjustments to findings from mainstream literature, assessment resources and interventions in its application to suit the specialist needs of individuals with an intellectual disability.

It's about being adaptive in the fact that - because of the population group we know that there's not a lot of research in certain modalities of treatment, so it's sometimes looking at best practice, looking at the evidence base and knowing how you can adapt it to your current client or the group of people you're working with. (Focus group 2, Government)

It's that trial and error as well with our clients. We can try something that's already used in mainstream and then see whether it works or doesn't work with our clients and then try and adapt it even more that way as well. (Focus group 7, NGO)

Discussion

This study aimed to investigate psychologists' views on best practice in dual disabilities. Australian psychologists from disability settings were generally found to be cognisant of clinical practices that appear aligned with EBP where theoretical and conceptual models, available research and professional guidelines with client and clinician characteristics are integrated (American Psychological Society, 2005). Overall, findings also revealed that perceptions of best practice with individuals with dual disabilities were generally consistent across government and non-government disability settings. Furthermore, best practice discussions overall appeared in line with current national and international best practice guidelines for working with people with an intellectual disability

(e.g., Department of Developmental Disability Neuropsychiatry, 2014; National Institute for Health and Care Excellence, 2016).

Adaptations to mainstream practice were frequently reported as part of psychologists' clinical practice. This draws parallels with the mainstream literature where adaptations to mainstream practices were also found with other specialist client groups such as individuals with complex personality disorders being treated for mental health conditions (Tyler & Mulder, 2006), and for individuals with co-morbid traumatic brain injury and post-traumatic stress disorder (Carlson et al., 2011).

The role of government psychologists compared with non-government psychologists typically involved more opportunities for direct liaison with mainstream mental health services. Given this, it was not surprising that government psychologists reported more barriers to accessing mental health services for their clients and interagency collaboration difficulties as this may have been more noticeable within their roles in government organisations. Furthermore, collaboration with other professionals and stakeholders was considered standard practice. Such collaborations are consistent with a systemic approach to intellectual disability care involving partnerships with carers, support staff and other professionals while synthesising knowledge of the client and clinical expertise (Kroese, Rose, Heer & O'Brien, 2013). In relation to mental health assessment for individuals with an intellectual disability, psychologists reported utilising a holistic approach which acknowledged the heterogeneous nature of individual disability presentations.

Compensating for a Paucity of EBP in Intellectual Disabilities

Given the limited EBP available in the field of mental health and intellectual disabilities, a majority of psychologists in the present study displayed resourcefulness in compensating for this paucity. Drawing on expert opinion and seeking formal and informal peer consultation was uniformly reported across work settings. It is not surprising to find

that psychologists working in government disability agencies reported referring to research to inform their practice given free access to online journal databases in government workplaces. Although access to research was also noted by non-government psychologists, these clinicians often relied on peripheral means to access research literature as access to research databases were not always freely available.

Adaptations to mainstream practice as previously discussed also led to the development of practice based evidence. Although most practising psychologists were not in the position to conduct direct collaborations with researchers in the intellectual disability field given their primary roles as front-line clinicians, both government and non-government psychologists described a process of modifying mainstream practice and obtaining pre and post measures to ascertain the efficacy of modified practices in line with EBP. Given the lack of mention of interactions with researchers by participating psychologists, more formal links between clinicians and researchers will assist to bridge the research to practice gap. For instance, collaborations between research units and disability organisations can be established in order to test and translate tailored interventions in the community. In New South Wales, this has recently been demonstrated via a partnership between the public disability, health and education sectors, whereby inter-departmental collaboration involved the examination of the efficacy of the Stepping Stones, Triple P program in school settings, run by clinicians from the disability sector, and evaluated and disseminated by researchers in the health sector (Dossetor, Caruana, Ray, Gomes, & Watson, 2013).

Study Strengths and Limitations

There is a notable dearth of research which has investigated psychologists' views and adherence to EBP guidelines in working with clients with an intellectual disability. This is an important area of investigation given the complexities that arise when working with this specialist group. Accordingly this study is the first of its kind to address clinical practices of

psychologists working with individuals with an intellectual disability and co-morbid mental health concerns and explore perceptions of best practice. Mental health in conjunction with an intellectual disability is often viewed as a challenging area for practising clinicians (Costello & Bouras, 2006) and this study provides more clarity into the nature of the additional considerations for clinical practice. In particular, utilising a person centred approach to combat the complex and unique presentations of each individual with an intellectual disability, making reasonable adjustments to mainstream practice, and collaboration with a range of stakeholders were vital in meeting the needs of this population.

The findings from this study also need to be considered in context of several limitations. It would have been beneficial to have had representation from psychologists in mainstream mental health settings such as local area hospital and community health settings given that a majority of individuals with dual disabilities typically access such services. Second, considering that recruitment of psychologists was based on psychologists working in government and non-government organisations in the metropolitan area of New South Wales, Australia, findings are not necessarily generalisable across other states and rural areas in Australia and other countries. Nonetheless, this study provides insight into how clinical practice can be adjusted to meet the complex needs of individuals with dual disabilities and compares current reported practices to international and national benchmarks for best practice (e.g., Department of Developmental Disability, 2014; National Institute for Health and Care Excellence, 2016).

All studies involving reports on participant's own experiences and views pose the possibility of the effects of social desirability. It should be noted that the facilitator of all focus groups was a psychologist in the intellectual disability field and some focus groups were conducted amongst peers in the same workplace and disability service networks. As a consequence, participating psychologists may have been less inclined to elaborate during

their discussions due to perceptions of assumed knowledge of the focus group facilitator. Alternatively, participating psychologists may have experienced social pressure to appear more in line with best practice standards than what their usual clinical practice dictates in the presence of their peers. Furthermore, the focus of this study was on examining psychologists' views and reported best practices when working in the intellectual disability field rather than on direct and observable practices of clinicians. Hence, it is beyond the scope of this study to explore implementation of best practices on a practical/objective level.

Implications and Future Directions

The findings from this study have implications for reviewing EBP guidelines in relation to individuals with an intellectual disability and co-morbid mental health concerns. Findings suggest that many psychologists working in disabilities do not see their role as conducive to mental health diagnosis. Although skilled in describing components to best practice for clients with an intellectual disability with dual disabilities, this was not reflected in reported mental health assessment practices. Mental health assessments were often left to psychiatrists with some psychologists seeing their role as facilitative. Interestingly however, in an Australian study which examined psychiatrists working with people with an intellectual disability, psychiatrists reported a lack of confidence in mental health assessment and diagnosis with the intellectual disability population (Edwards, Lennox & White, 2007), which is comparable to the current study's findings. Given psychologists in this study had an average of 15 years of experience working in intellectual disabilities; it is unlikely this lack of confidence is a reflection of a lack of experience. However, almost two thirds of participating psychologists only held undergraduate psychology qualifications and thus may not have received formal training in mental health diagnosis. Together with the reported diagnostic complexity of clients with intellectual disability, it is not surprising that confidence levels in mental health diagnosis were low. Furthermore, differential diagnosis

can often become increasingly difficult with co-morbid presentations (Matson & Williams, 2013). Given this, clearer evidence based guidelines on mental health assessment for individuals with dual disabilities are required to support psychologists in their current roles. Clinical psychologists trained in mental health assessment and diagnosis specialising in intellectual disabilities may also have a role to play in providing support and training to fellow psychologists working in the field to increase competency in mental health assessment.

It is widely known that mainstream mental health services often lack the expertise to meet the specialised needs of individuals with an intellectual disability in Canada, Australia, United States as well as in the UK (e.g., Hemmings, Bouras & Craig, 2014; Iacono et al., 2014; Lunskey et al., 2010). Internationally, there has been a gradual shift towards provision of more specialist services to address the mental health needs of individuals with an intellectual disability (e.g., Brown, MacArthur, McKechnie, Hayes, & Fletcher, 2010; Lunskey et al., 2010). For instance, in the UK, individuals with profound or severe intellectual disabilities tend to receive their mental health services from specialist intellectual disability health service which include community and inpatient services. Individuals with a mild to moderate intellectual disability may access intellectual disability services or mainstream mental health services, or a combination of both (O'Brien & Rose, 2010). Consequently, it is unrealistic to rely solely on mainstream mental health services to meet all mental health needs of individuals with an intellectual disability (Brown et al., 2010), particularly given limits in resources and expertise in dual disabilities (Lunskey et al., 2007).

Notwithstanding the confidence issues elicited by psychologists in the current study, the findings further suggest that psychologists are resourceful in compensating for limits to EBP in intellectual disabilities. Despite this, improved access to available research in intellectual disabilities in a timely and user-friendly manner would contribute to fast tracking

the research to practice pathway. One suggestion would be for professional psychological organisations and interest groups in intellectual disabilities to produce regular research updates of latest research with links to the location of research articles. This would assist clinicians who are generally time poor to keep up to date with current research literature. Collaborations between researchers and those providing direct services to individuals with an intellectual disability will also assist in bridging the research to implementation gap. One such initiative can be found with the Two-Way Bridge where clinicians are invited to provide feedback on the efficacy and application of empirically supported treatments for a number of mental health disorders (Goldfried et al., 2014). Another example in the mainstream literature designed to assist with practice based evidence is the Clinical Outcomes in Routine Evaluation-Outcome Measure (Barkham et al., 2001), a pan-theoretical measure used across professions to provide outcomes on a range of treatment modalities. Given the frequent mention of use of outcome measures by psychologists, the adoption of similar initiatives in the intellectual disability field will assist modifications to mainstream practice to be implemented in a consistent and structured manner. In doing so, this will support psychologists working in intellectual disabilities to effectively implement EBPs on par with international standards.

In conclusion, the outcomes from this study add to our understanding of best practice perceptions and applications by psychologists in the intellectual disability field. The findings support practice based evidence in its contribution to the growing evidence base of dual disability literature.

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APPENDIX B

Focus Group Questions Used

- 1. What does it mean to implement best practice? Please comment on how does this relates to your current clinical practice.**
- 2. How does best practice apply to working with people with comorbid intellectual disability and mental health concerns?**
 - How does this apply to mental health assessment for people with an intellectual disability?**
- 3. What do you do/draw upon when evidence-base is lacking when working with people with an intellectual disability with mental health concerns?**

Bridging Chapter following Chapter 4

The objective of the first part of this second phase of research was to examine adherence to national and international best practice standards in dual disabilities by Australian psychologists working with clients with an intellectual disability. A further aim was to examine ways in which psychologists adapt to limited evidence based guidance in the dual disability field. Findings revealed that overall, psychologists reported practices that aligned with international practice guidelines. For instance, psychologists were able to identify special considerations relating to best practice with individuals with an intellectual disability and comorbid mental health conditions. Psychologists also described a variety of ways to compensate for limited evidence base in dual disabilities in their clinical work.

Although in theory, reported clinical practices of psychologists appear to be in line with international best practice standards, it is not known whether adherence issues exist. Therefore, for the second part of this second phase of research, the aim was to investigate adherence and non-adherence factors relating to best practice implementation in the context of the psychologists' work environment. Organisational factors to evidence based practice implementation were also investigated to further understand the impact of organisational factors on clinical practice in dual disabilities. Together, this will provide insight into the disability and mental health service delivery landscape in Australia and provide a useful comparison with the international landscape. Moreover, it will facilitate in identifying gaps and barriers to service provision which need to be addressed in order to meet the needs of individuals with an intellectual disability in Australia.

Chapter 5: Phase 2 Paper 2

Best Practice Adherence and Workplace Facilitators and Hindrances for Psychologists working with Individuals with Intellectual Disabilities and Co-morbid Mental Health Concerns

Joyce Man & Maria Kangas⁴

Centre for Emotional Health, Macquarie University

Keywords: Best practice, Intellectual disability, mental health, organisation, psychologists

* Manuscript submitted

⁴ This is to confirm Joyce Man is the first author and has completed all field work, primary coding and data analysis and the first full draft of this paper.

Abstract

Background: A number of practice guidelines are available to set the benchmark for best practice when working with individuals with an intellectual disability and co-morbid mental health concerns. However, dissemination and implementation of such guidelines in the context of psychologists' work settings remains unknown.

Study aims: The aim of this qualitative study was to investigate adherence to current practice guidelines by Australian psychologists working with this specialist population and explore organisational factors that may facilitate or hinder evidence based practice implementation.

Method: Thirty eight Australian psychologists from government disability and non-government disability organisations working primarily with individuals with intellectual disability participated in eight semi-structured focus groups. Psychologists were presented with a summary of a current Australian practice guideline in dual disabilities and asked about their adherence and barriers to this guideline as well as workplace factors impacting on its implementation.

Findings: Psychologists reported views consistent with current Australian best practice standards but noted a number of barriers impacting on adherence. Facilitators and hindrances to best practice implementation were discussed in relation to views on applicability of current guideline, organisational level hindrances, organisational resources and training, organisational operations and systemic considerations.

Discussion: Findings highlight the importance of a collaborative and systemic approach in order for practice guidelines to be effectively implemented for psychologists working in the field of intellectual disabilities. Implications for policy development and training are discussed.

Introduction

Psychologists are trained at varying levels of evidence-based practice in the assessment and treatment of mental health concerns. In the field of intellectual disabilities however, there appears to be an evident gap between research and practice in relation to working with the dually disabled population (i.e., individuals with an intellectual disability and co-morbid mental health concerns) (Jensen-Doss & Hawley, 2010). Although international guidelines are available such as in the United Kingdom (e.g. National Institute for Health and Clinical Excellence, 2016) and in Australia (e.g. Department of Developmental Disability Neuropsychiatry (3DN), 2014), dissemination and utilisation remains poor. In particular, no consensus exists regarding differential assessment and diagnosis of mental health concerns co-morbid with an intellectual disability. In 2014, an Australian national practice guideline was launched to guide clinical practice when working with individuals with ID and co-morbid mental health concerns (3DN, 2014). This guide aimed to establish benchmarks for best practice for clinicians working with mainstream services who came in contact with individuals with an intellectual disability and co-morbid mental health problems and their families. The guide was developed out of consultation with experts in the field across the health and disability sector and aimed to improve accessibility of mainstream mental health services for people with dual disabilities and their carers.

Despite the availability of practice guidelines, a number of factors can also impact on adherence. A review of mainstream literature examining barriers to evidence based practice implementation in the human services found a number of organisational barriers which included inadequate agency resources; organisational culture; the research environment; and inadequate supervision (Gray, Joy, Plath, & Webb, 2013). Glisson and Schoenwald (2005) highlight the

importance of organisational culture and recognise that mental health treatments are implemented by clinicians within a social context. This social context can have a significant impact on treatment adoption. Organisational cultures that were more engaged and less stressful were associated with more positive clinician attitudes toward evidence based practice implementation (Aarons et al., 2012). Similarly, Gray and colleagues (2013) note the importance of a supportive organisational culture with adequate supports, resources, training, and availability of supervision for practitioners in facilitating evidence based practice implementation.

In the area of mental health assessment for people with an intellectual disability, the work setting may also impact on certain clinical practices of psychologists (Man, Kangas, Trollor & Sweller, 2016) [*Chapter 2 of thesis*]. Findings from a national survey of psychologists working with adults with an intellectual disability found differences between psychologists from private practice, non-government organisations and government disability services in their perception of adequacy of resources to assess and diagnose mental health disorders in individuals with an intellectual disability in their work settings (Man et al., 2016) [*Chapter 2 of thesis*]. Given these findings, it is clear that factors influencing evidence based practice implementation need to move beyond individual clinician factors to consider the impact of the organisation. Further investigation around organisational factors would be helpful in understanding what hinders and facilitates evidence based practice implementation in the intellectual disability field.

Aims of current study

Studies examining evidence based practice implementation tend to focus on clinicians' general views on evidence based practice adoption without reference to specific practice

guidelines. There is minimal research to date which examines evidence based practice implementation in the field of intellectual disabilities. In fact, no study to date has examined clinician adherence to the standards and practices laid out by specific national and international practice guidelines developed for this specialist population. In order to address this notable gap in this field, the aims of this study were twofold: 1) To investigate both compliance and barriers to adherence by psychologists regarding their implementation of a current Australian best practice guideline for working with people with an intellectual disability and co-morbid mental health disorders (3DN, 2014); and 2) to examine workplace barriers and facilitators to best practice implementation.

Method

Participant Characteristics

Eight focus groups were conducted with a total of thirty eight (8 males, 30 females) psychologists in New South Wales, Australia. Four focus groups were conducted with government disability organisations (20 participants) while four involved psychology/therapy teams within non-government organisations (NGO) (18 participants). Psychologists' clinical experience ranged from one to 36 years ($M = 13.5$, $SD = 9.3$), while experience specific to the intellectual disability population ranged from two to 30 years ($M = 14.5$, $SD = 8.6$). Duration in current work role varied similarly from one to 29 years ($M = 7.7$, $SD = 6.5$). Two-thirds of participants (68%; $n = 26$) were currently employed as psychologists, 18% as behavior support specialists ($n = 7$), whilst the remaining 14% held other roles ($n = 5$) including senior and managerial positions. Caseloads with clients with co-morbid intellectual disabilities and mental health concerns ranged from 5 to 100% ($M = 65\%$, $SD = 26.2$). Overall, the majority of

participants held undergraduate psychology qualifications (66%), while 34% had postgraduate psychology qualifications.

Measures

Participants completed a demographic questionnaire with items relating to academic training, work setting, experience, proportion of caseloads with dual disabilities, and previous training and use of a range of treatment modalities. Psychologists in the same work setting then took part in semi-structured focus groups as part of a larger study (comprising Phase two of this research project). For the purposes of addressing the current study aims, one question examined general current adherence and non-adherence to a recent Australian practice guideline (3DN, 2014) when working with individuals with ID and co-morbid mental health concerns as well as when conducting mental health assessments with this population. A second question explored workplace facilitators to best practice implementation while a third question explored workplace hindrances to best practice in the dual disability population. See appendix C, p. 164 for a list of focus group questions used.

Procedure

Following institutional ethics approval, clinical and generalist psychologists working with adults with an intellectual disability in Australia with a minimum of two years of registration were recruited for the study. Participants were recruited through the first author's professional networks as well as via circulation to non-government organisations and interest groups of professional psychology organisations within New South Wales. Once participants provided informed written consent, each of the focus groups consisting of three to six psychologists were conducted in their corresponding workplaces. Following completion of the demographics questionnaire, participants were presented with a summary of The Guide (3DN,

2014) prior to commencement of semi-structured focus group questions. Discussions were audio-taped lasting for a maximum of two hours. A summary was given at the conclusion of each focus group discussion to allow participants to clarify and provide further input.

Data Analysis

Following transcription of focus group audio recordings, qualitative analysis of each transcript was undertaken. Thematic analysis (Braun & Clarke, 2006) was used to identify themes from the three focus group questions. N Vivo software (version 10) was used by the first author to manage the coding process during all phases of the thematic analysis. Derived themes and sub-themes were also reviewed by the co-author. Where discrepancies emerged, discussions followed until agreement was reached.

Results

A total of five themes and thirteen sub-themes were generated following discussions around adherence to an Australian best practice guideline on dual disabilities (3DN, 2014) and work place factors impacting on evidence based practice implementation. The themes and subthemes, as well as sample quotations are presented in Table 1.

Table 1

Themes, Subthemes and Supporting Quotes

Themes	Sub-themes	Supporting Quotes
Views on applica-bility of current practice guidelines	Guide applicability	I don't have a graphic guide so it doesn't actively have a role in the way that I approach my work. But reading the points, I think it pretty much applies. (NGO psychologist, Focus group 6)

Themes	Sub-themes	Supporting Quotes
Organisational level hindrances	Skepticism and uncertainty	<p>Alright where's the training programs that follow them up? So when you reach one, action. Who, what, when and where? (Government psychologist, Focus group 2)</p> <p>Then how Health fits into that individual packaging ideology. Some of their clients will be accessing the NDIS as well. So how you purchase a service for that, don't even go there. (Government psychologist, Focus group 1)</p> <p>There will be those issues of coordination, collaboration and so on, but everybody is busy and this all takes time. And actually the planner is not going to pay for that so, from our point of view, well, and why should they pay for all that? (NGO psychologist, Focus group 8)</p>
	Restructuring problems	<p>There is this high staff turnover in the disability sector so you might say you've just done training in dual diagnosis but it was two years ago and was completely different team of staff. (NGO psychologist, Focus group 5)</p> <p>We're the only team still standing in its current format how it was from a region. But in the other patches around the state, they don't have access to that expertise anymore. It's been lost, because it's been diffused. The person who had that expertise may no longer live in their district, but someone else is, so they can't access it. (Government psychologist, Focus group 1)</p>
	Team dynamics	<p>I'm working with people from the young people leaving care program and the managers there are also the case managers, so we work very closely to identify what services the person requires so in terms of the interdisciplinary approach that's what we do on an ongoing basis. (NGO psychologist, Focus group 5)</p> <p>I try to work as multi-disciplinary as possible but he (<i>sic</i>) is saying that I've never had a multi-disciplinary client discussion with a team. (Government psychologist, Focus group 3)</p>
	Role limitations	<p>And sometimes we don't get the time we need with teams particularly in a crisis period having access to staff when we really need access to staff to help turn the corner, is when we're most restricted to just being able to get timely change. (NGO psychologist, Focus group 7)</p> <p>I guess we're limited in terms of the research we can do. We worry about there not being evidence out there that we really are limited in how much of that we can do. (Government psychologist, Focus group 1)</p> <p>And I guess that's what our role is. At the moment we are not diagnosing. But we are basically identifying that the client has Mental Health issues along with this ID and that whom should be turn to for help. (Government psychologist, Focus group 3)</p>

Themes	Sub-themes	Supporting Quotes
Organisational resources and training	Access to expert panels, consultations and professional resources	<p>We attend different kinds of interdisciplinary meetings or things like that where we can see what everybody else is doing, share resources, share knowledge, information, all that kind of stuff. (NGO psychologist, Focus group 7)</p> <p>We have the advisory committees and we talk about these system issues all the time. It goes up through the line - going from local services to the advisory one that goes to the state and all the rest, saying where can we make better linkages? (Government psychologist, Focus group 2)</p> <p>We also have free access to journals. (Government psychologist, Focus group 3)</p>
	Funding limitations	<p>There is a lack of real support of - supporting people accessing good professional development. (Government psychologist, Focus group 2)</p> <p>And also you need more time to assess somebody with an ID, especially in an acute mental health setting, there's just not that time for that to occur in a flexible way. (NGO psychologist, Focus group 7)</p> <p>Sometimes we have to work with a lot of limitations. I think with doing Medicare, with one of the points raised in the guide is that. (NGO psychologist, Focus group 5)</p>
	Training	<p>Here they talk about the skills required for the clinician. I agree with all of it, the in depth knowledge of interactions between health and mental health conditions, high level of expertise, but if someone doesn't have that, there's nothing about how do they go about getting that information, or how do they go about getting that training, or who do they go to within the system. Because I guarantee you most clinicians don't have all of this or aren't aware of all of this. (Government psychologist, Focus group 1)</p> <p>We have a very large training section that staff can attend, external people can attend as well. Training on things like working with people with a disability. So that there is that professional development for staff. (NGO psychologist, Focus group 8)</p> <p>But we are in this position where we actually develop our own training and develop our own tools and make sure our staff have the mental health first aide training in intellectual disabilities. (NGO psychologist, Focus group 5).</p>

Themes	Sub-themes	Supporting Quotes
Organisational operations	Organisation values	<p>You don't have to convince people within (government disability organisation) that mental health is something that's real and present and may need to be considered. There is that general awareness that it is something our population can suffer from, which I think facilitates some of that work as well. (Government psychologist, Focus group 1)</p> <p>Sometimes it's a hindrance getting people to understand, sometimes that people with an ID and mental health can still try doing things they want to do. There's that reactive focus whole all their life. (Government psychologist, Focus group 1)</p> <p>It's really about being authentically interested in getting the best possible outcome for that person. At the end of the day, that's what it's about. (NGO psychologist, Focus group 8)</p>
	Work culture	<p>I think our organisation particularly from that medical point of view, with medication, we have a strong policy around restricted practices. (NGO psychologist, Focus group 8)</p> <p>You know little things like having flex days and access to holidays and knowing that when I feel burn out I can apply for a holiday and I don't have to argue with anyone about that. (Government psychologist, Focus group 3)</p>
Systemic considerations	Collaboration	<p>It's best practice to get as many accounts from people within that person's support network if you can. (Government psychologist, Focus group 4)</p> <p>There's collaboration, particularly liaising with psychiatrists and GP's and other people who are involved with this mental health concerns. (NGO psychologist, Focus group 7)</p> <p>I think just that use of acronyms and disability specific language that we use, at mental health they just look at us and go, what are you talking about? (Government psychologist, Focus group 4)</p>
	Service access barriers	<p>I mean, my experience with an acutely unwell client is that it's the more experienced mainstream staff who seem to have that overshadowing rather than the less experienced staff who are like "This is not normal". (Government psychologist, Focus group 4)</p> <p>There are not enough Psychiatrists or paediatricians who understand Intellectual Disability. (Government psychologist, Focus group 3)</p> <p>I had someone many years ago who was discharged. They (mainstream mental health service) just said, do you happen to have any intellectual disability, like that was not even remotely who that person is when they're mentally well. There's just that straightaway assumption that it's ID, let's send them back to disability services. (NGO psychologist, Focus group 7)</p>

Themes	Sub-themes	Supporting Quotes
	Inadequacies of medical model	<p>They administer pharmacological intervention straight away rather than doing non-pharmacological interventions. It's like a quick fix for them. (NGO psychologist, Focus group 7)</p> <p>When I worked for mental health services I think there was - from about 30 case managers, I think there was maybe two that had ever worked with anyone with an intellectual disability. The rest had never. So there's a whole lot of sort of fear and lack of knowledge around how you communicate with them. (Government psychologist, Focus group 4)</p> <p>You walk in to do an assessment, I guess some of the tools are intense and they don't use basic language. (Government psychologist, Focus group 3)</p>

1. Views of Applicability of Current Guideline

Psychologists were presented with a summary of The Guide (3DN, 2014) and asked to comment on whether the main principles were in line with their current practice with individuals with an intellectual disability and co-morbid mental health concerns. The first theme related to discussions regarding clinician views of The Guide's relevance and applicability. Two sub-themes emerged pertaining to whether The Guide was relevant, as well as skepticism and uncertainty related to guide application.

Guide applicability.

Psychologists from all focus groups reported agreeing with many of the principles and recommendations as outlined in The Guide and reported its application in some form in their own practice. One NGO psychologist noted "*there is nothing here that I go, 'Oh gee, we don't do that.'* or '*Oh, we haven't thought of that.'* or, '*This is certainly not something that we would agree to.'* I think, yes, we've been aware of this document" (Focus group 8).

Skepticism and uncertainty.

Some psychologists expressed doubt around the effective application and dissemination of The Guide (3DN, 2014) across all relevant service sectors. Despite

agreeing with the principles outlined within the guideline, some psychologists expressed skepticism around how the guide would be put into practice. One government psychologist exclaimed *“I think to me they're in line with what we do. It's about the implementation of that. That's the difficulty”* (Focus group 1).

Psychologists also expressed concerns in relation to implications of the National Disability Insurance Scheme having a negative impact on service delivery. (The NDIS is an insurance scheme introduced in Australia for people with permanent disabilities designed to provide individualised access to disability services via government funding) (National Disability Insurance Scheme, 2014). Some held concerns around the inability to sustain current best practice standards under the NDIS service model. One NGO psychologist noted *“The transition to NDIS has impact because we're changing the practice model which is under review where we will be moving to a more commercial based business model, we won't have time for this collaborative, holistic approach”* (Focus group 5). Many psychologists commented on the foreseen diminished quality of services for individuals with an intellectual disability under the NDIS specifically in relation to psychological services, a reduction in funding, time and difficulties with continuing collaborative work with the health sector were seen as some barriers to best practice given that the NDIS does not provide funding for existing health services. One NGO psychologist commented

I think this is one thing that a lot of time is being spent on at the moment and it is with the NDIS, in particular it is that a) how long can you spend with the clients, so it's not necessarily what you as a clinician may think, it's what money that person has been given by planners who do not make the diagnosis, who just talk with the family, who may or may not actually understand what would be most helpful or know. They may not know what they don't know, for example. So they're not going to ask for it. (Focus group 8)

2. Organisational level Hindrances

The second theme related to ways in which the psychologist's workplace systems created barriers in best practice adherence. Three sub-themes emerged.

Restructuring problems.

Difficulties arising from high staff turnover and organisational restructuring were reported by some psychologists in retaining expertise in their organisation. One government psychologist commented "*clinicians have gone off and done some fancy pants training in a particular area and then they go and work privately straight after. So we lose - so to keep that knowledge within government I think is tricky and especially in this environment*" (Focus group 1). Government psychologists also expressed concerns in relation to the continuation of best practice delivery following the closure of state government operated disability services in New South Wales due to the NDIS.

Team dynamics.

A majority of psychologists reported an inter/trans disciplinary team approach and working in collaboration with external clinicians was conducive to best practice. One government psychologist described "*trying to get everyone on the same page working together, rather than working independently towards independent goals, and helping the family to understand, you know, how it all fits together and works together*" (Focus group 4).

Managerial support was considered important by many psychologists in upholding best practice standards in the workplace. For some psychologists, a conflict arose between adhering to professional codes of conduct and adhering to workplace mandates. One government psychologist expressed "*Sometimes there's a disjoint between our professional psychology code of conduct and the (organisational) structure with wait lists and handovers*

and the expectations” (Focus group 1). Government psychologists in particular noted varying understanding and adherence to best practice across levels of the organisation. One government psychologist noted *“as a psychologist I know I can provide to a manager or fellow colleague specific info that is really relevant but it's almost like at times structure to a hierarchy doesn't allow them to ones it accept that information and to me that's really does hinder best practice”* (Focus group 3).

Role limitations.

Some psychologists experienced their work role as hindering best practice delivery. At times, their clinical role did not seem well defined, while for others there were limited opportunities for direct therapeutic work with clients with an intellectual disability. One government psychologist reflected *“we have a lot of responsibility compared to other disciplines – they're mainly assessing like, give recommendations whereas I feel as a Psychologist this is not necessarily that clear cut because we are looking at behaviour”* (Focus group 3). Others described their roles were limited when it came to conducting mental health assessments which involved more data gathering rather than mental health diagnosis. One NGO psychologist described *“we don't have the experience or the skill to be able to conduct the same (mental health) assessment”* (Focus group 6).

3. Organisational Resources and Training

This third theme related to discussions around the impact of the presence and absence of organisational resources and training on adherence to best practice in dual disabilities. Three sub-themes were generated from this theme; one which reflected factors facilitating best practice, whilst the other two subthemes related to resource and organisational barriers in implementing best practice.

Access to expert panels, consultations and professional resources.

Many psychologists reported access to expert panels, consultation and resources/guidelines facilitated adherence to best practice. Psychologists noted the benefits of having access to experts in dual disabilities and professional development opportunities to support their work with clients with complex needs and dual disabilities. These expert panels allowed *“the case can be presented and then the panel will not only provide input into best practice but also can help facilitate some of that sometimes”* (Government psychologist, Focus group 4).

Funding limitations.

Contrary to the first subtheme, many psychologists reported financial limitations negatively impacting on best practice delivery. Non-government psychologists in particular reported more pressure as a result of restrictions to service provision under a billable service; *“there is that pressure of billable hours and how you do that, which doesn’t always fit comfortably with best practice as we’ve known it in the past”* (Focus group 8).

Psychologists also noted the impact of limited funding on service quality and access to mainstream mental health services for their clients with an intellectual disability, for example, inpatient hospital bed availability and impact on clinician time available to conduct mental health assessments. A detrimental impact on the quality of mental health assessment was also raised. One government psychologist expressed concern that *“there’s not going to be any room for further assessments”* (Focus group 1).

Training.

Limits in training in intellectual disability of mainstream mental health professionals were reported as a major barrier to best practice adherence. Notwithstanding, government and non-government disability psychologists also admitted to limitations in their

knowledge, training and skills in dual disabilities. In addition to limitations in their own clinical skills which were largely attributed to limited specialty training in dual disabilities, this was also reported to be evident in other professional workers in the disability sector, such as direct support workers. One NGO psychologist commented “*we come across very often, staff who don’t really have any training in dual diagnosis, still they might see some of the symptoms as naughty behaviours and provide support inappropriately and make the situation worse*” (Focus group 5). Psychologists also noted the role of professional training and the provision of this in the workplace in the support of best practice implementation.

4. Organisational Operations

This fourth theme related to the role of workplace systems, culture and values on facilitating and hindering best practice implementation. Two sub-themes emerged.

Organisation values.

Values promoted by the organisation were reported to serve to facilitate best practice for both government disability and non-government psychologists. However, organisational values promoted by non-government organisations were reported to be more in the forefront of their clinical practice. Some non-government psychologists reported a sense of authenticity which governed their work to “*get the best possible outcome for that person*” (Focus group 8).

Some psychologists also reported unhelpful attitudes regarding individuals with an intellectual disability of some professionals and service providers. For instance, some claimed mainstream mental health staff held unhelpful and inaccurate views of people with an intellectual disability while others ignored the individuality of the client. One example involved “*some doctors, psychiatrists will say they shouldn’t be living in the community they should be living in institutions*” (NGO psychologist, Focus group 5).

Work culture.

Attitudes and consensus around workplace practices were reported to facilitate best practice. For some, this involved working within a culture where a systems approach and consulting with stakeholders for an individual with an intellectual disability was considered standard practice. For others, this meant working with clear clinical outcomes. Others reported working within an environment which valued the importance of professional self care, with intake and referral systems in place to address different service needs of their clients as well as being given sufficient time to conduct assessments and to access client records. For instance, one government psychologist described it being “*okay to create the time and space to do a file review*” (Focus group 4).

5. Systemic Considerations

The fifth and final theme related to discussions around the impact of the wider service system on adherence to best practice standards. Three sub-themes were generated in relation to this.

Collaboration.

A majority of psychologists recognised the role of collaboration with clients, families and other professionals and services within the individual’s support system in facilitating best practice adherence. Disability psychologists noted many challenges with collaborations with mental health clinicians and mainstream mental health services.

Government psychologists in particular experienced challenges in creating long term collaborative connections with mainstream mental health services. Many attributed the success of established inter departmental connections to relationships with individual experts in mental health services or specialist services such as psychiatrists specialising in dual disabilities. Concerns were raised on the sustainability of such collaborations should these

individuals no longer choose to work in the intellectual disabilities field. One government psychologist explained it was about “*finding the right person in the system and it's more to do with that person and their personality and their willingness to help than it is about the system allowing you to access that service*” (Focus group 1).

Some government disability psychologists described operational differences between disability and mental health services that impeded on effective collaboration. Some operational differences reported included differences in terminology, differences in assessment methodology, varying awareness or implementation of the Memorandum of Understanding (NSW, 2010) and misunderstandings of the resources and operations of disability services by mainstream mental health service staff.

Service access barriers.

Psychologists reported many challenges to best practice adherence came from their experiences with mainstream mental health services. Access barriers to these services for individuals with an intellectual disability were frequently noted, and when acquired, were often considered unsuitable for individuals with an intellectual disability. One government psychologist stated that contact for clients with intellectual disability often involved “*a series of short admissions that boomerang back between the disability service and the mental health service*” (Focus group 1).

For individuals with dual disabilities, when attempting to access mainstream mental health services, some psychologists described a tendency of hospitals to refer back to disability services for the joint client’s mental health management. Difficulties in accessing mainstream mental health services because of the individual’s intellectual disability were noted. One NGO psychologist described “*The public system will say we cannot have them, and yes we run groups for people with personality disorders but because your clients have intellectual disability they won’t be suitable for this group*” (Focus group 5).

Inadequacies with the medical model.

Many examples were given around challenges faced by individuals with dual disability in hospital settings such as a lack of flexibility in accommodating to their specific needs. A majority of psychologists noted adherence to a strict medical model in the mental health sector compromised service quality and adherence to best practice standards. At times, this involved minimal consultation with support people and limited time spent with the patient with an intellectual disability by mental health professionals in mainstream mental health settings.

In addition to the reported inadequacies with mainstream mental health services in meeting the needs of individuals with dual disabilities, specialist services and experts in the field were not exempt from criticism. It was largely reported that specialist services were few and far between and often inaccessible to those who needed the service. Such services were also often described as stretched and available only for consultative support to individuals and their families. One government psychologist exclaimed “*I seriously was so disappointed. He only works there - he's only there one day a week basically*” (Focus group 2).

Discussion

The objective of the study was to examine psychologists’ adherence to a current Australian practice guideline for individuals with an intellectual disability and co-morbid mental health concerns and workplace factors impacting on best practice implementation. The results informing the first aim of this study, adherence to a current Australian best practice guideline (3DN, 2014) revealed that psychologists’ attitudes towards best practice were generally consistent with the guideline, however many hindrances to implementation were reported. Many psychologists highlighted adherence difficulties stem from a collective understanding that a cross-agency, collaborative approach between disability and health

services was needed. Many psychologists noted difficulty advocating for their clients with an intellectual disability to access mainstream mental health services. Some attributed this to a lack of training of professionals in the health sector in intellectual disabilities while others cited the limited availability and resources of specialist services. A number of barriers relating to collaboration between disability and health services were also reported. This finding is consistent with previous literature highlighting the impact of the dichotomising of services for individuals with an intellectual disability into disability-welfare and therapy focused supports and health-medical related services (e.g., Mohr, 2002; Torr, 2013). As suggested here, such dichotomising of services can result in individuals with dual disabilities falling short of a quality mental health service where both service types do not always assume responsibility for servicing this population.

Furthermore, the skepticism towards the implementation of The Guide (3DN, 2014) in the field of intellectual disabilities is not surprising given the recent release of this framework and the often cited delay between research and practice. Best practice in the field of intellectual disabilities is widely acknowledged as involving inter disciplinary, cross agency and collaboration with multiple stakeholders (Mohr, 2002). This complexity creates additional systemic barriers hindering the application of The Guide (3DN, 2014).

In relation to the second aim, organisational level hindrances, resources and training, operations and the service system posed to be both facilitative and hindering to best practice implementation. In relation to facilitative workplace factors impacting on best practice in dual disabilities, a work culture that placed value and supported evidence based practices were important facilitative factors. Consistent with the principles outlined in most practice guidelines in intellectual disabilities, working in a multidisciplinary team was seen to facilitate best practice with individuals with an intellectual disability. The organisation's values appeared to be of significance particularly for non-government psychologists who took pride in their authenticity when servicing individuals with an intellectual disability.

Being smaller organisations, non-government organisations may place more importance in their collective identity to distinguish themselves from other organisations. The clinical practices of psychologists working in government disability services on the other hand are mandated by state policies, practices and charters perhaps resulting in less focus on organisational identity.

In relation to workplace hindrances, a number of organisational barriers were highlighted. Inconsistency across levels of an organisation in implementing best practice principles was seen as a major barrier, in particular for government psychologists. This may be a result of working within a large agency with multiple layers of service delivery. Funding limitations and its implications on quality of service provision were also highlighted as hindering best practice. Limits in expertise in dual disabilities were also issues for a majority of psychologists. This finding is consistent with results from mainstream studies on barriers to evidence based practice adoption (Cook et al., 2009; Gray et al, 2013). Inadequate service structures and supports and limited clinical competency and access to training have also been identified as major barriers to the implementation of international practice guidelines on behaviour management in intellectual disabilities (Pilling, Marcus, Whittington & Murphy, 2015).

For mainstream mental health services, disability psychologists reported many examples of limited understanding and accommodation to the needs of individuals with an intellectual disability and their families. Disability psychologists reported receiving limited training in dual disabilities and some psychologists viewed their role as not inclusive of mental health assessments for individuals with an intellectual disability. This highlights the ongoing issue related to the limitations in expertise of both mainstream mental health and disability services in dual disabilities (Bennett, 2014). These findings also highlight the inadequacy of existing mainstream services in meeting the needs of individuals with dual

disabilities. Such findings are consistent with outcomes from a study comparing the views of consultant and trainee psychiatrists within a specialist intellectual disabilities model (in the UK) and a generic mental health model (in Australia) (Jess et al., 2008). Participants from the UK were found to hold positive views in the specialist intellectual disabilities service model in which they worked, showing flexibility in maximising service access to individuals with an intellectual disability and were knowledgeable and well trained in their work. The contrary was found for those working under an Australian generic mental health service model (Jess et al., 2008).

Given the recent shift in Australia to the NDIS where services for people with disabilities and their families are undergoing significant change, participating psychologists expressed concerns regarding its impact on the quality of psychological service delivery. Psychologists seemed skeptical of their own ability to maintain best practice standards as highlighted in current practice guidelines under a scheme where hours and sessions deliverable to an individual with dual disabilities are limited by allocated NDIS funding. Since the time the study was conducted, a further document (3DN, 2016) was launched detailing specific activities and competencies relating to the principles of The Guide (3DN, 2014) in an attempt to bridge the research to practice gap. Links to online training are also being made available to guide clinicians, support workers and families to better support the mental health needs of individuals with dual disabilities.

Study Strengths and Limitations

This study is one of the first of its kind to examine adherence of psychologists to a specific benchmark of best practice in dual disabilities. This study is also one of the first to examine organisational factors impacting on evidence based practice implementation in the field of intellectual disabilities. Findings will assist to shape future policy and practice

guidelines with the aim of increasing accessibility and application by clinicians working in the intellectual disability field.

The findings from this study also need to be understood within the context of its limitations. In the investigation of aim one, adherence to best practice guidelines were measured by participating psychologists' reported views and behaviours. No objective measures of adherence of clinical practice were used. Considering focus groups were conducted amongst peers in the same organisation, one must take into account the possibility of the effects of social desirability. Furthermore, it was not possible to obtain a representation of psychologists working in mainstream mental health settings. Doing so would have provided an important comparison between psychologists in disability and health settings regarding adherence and workplace factors impacting on best practice. In addition, the Australian practice guideline (3DN, 2014) used to set a benchmark for best practice despite sharing many similar principles to its international counterparts, was developed for clinicians working under an Australian service model which is not necessarily transferrable across all countries and service models. However, many countries are also currently transitioning to an individualised, self-managed service model for disability services (e.g., UK, US). Finally, The Guide (3DN, 2014) was developed with health service providers and clinicians in mind. Although many of the recommended practices can be transferrable to psychologists in the disability sector, some participating psychologists commented that the guideline appeared more relevant to practitioners in the health sector which may have influenced findings.

It is beyond the scope of this study to examine organisational compliance to best practice standards. Initiatives in the UK have been developed to serve this purpose in the form of organisational audits; e.g. Green Light Toolkit (National Development Team for Inclusion, 2013). In Australia, the Behaviour Support Plan Quality Evaluation Guide II

(BSP-QUEII) (McVilly, Webber, Paris & Sharp, 2013) is one example of a tool that has shown promise as a audit tool to evaluate the quality of behaviour support plans in community services. Further initiatives in Australia focusing more broadly on overall service standards would be useful and timely to ensure organisations are adhering to best practice standards for individuals with dual disabilities given their specialised and complex needs and changing landscape of disability service provision under the NDIS.

Implications and Concluding Remarks

The findings from this study have implications for policy development with reference to currently available practice guidelines. Policies relevant to individuals with dual disabilities written with awareness of organisational and systemic adherence barriers to evidence based practice implementation will be more likely to bridge the research to practice gap. One of the reported barriers involved a lack of uniformity in adherence and understanding of best practice principles across the disability and health sectors, and within all levels of individual organisations. Accordingly, this warrants inter agency training in policies and training provided across all levels of the organisation with emphasis on managerial positions supporting frontline staff with its implementation. Limited expertise in dual disabilities continues to be a major barrier impacting on the quality of services for individuals with an intellectual disability and their families as suggested by findings from this study. Training provided by the organisation must be specific to the needs of staff from a variety of professional backgrounds and roles. Inter-departmental/agency training will also provide opportunities to problem solve any issues interfering with effective collaborative engagement between health and disability sectors.

As suggested by the findings of this study, for a workplace to uphold high standards of practice for individuals with dual disabilities, ongoing professional development and provision of professional resources within a team culture that promotes evidence based

practice is necessary. These recommendations are particularly pertinent for organisations operating under insurance schemes such as NDIS in Australia aiming to establish expertise in dual disabilities. Given the restrictions on funding available to service individuals with dual disabilities, it is recommended that national policies stipulate minimum clinical competency standards for best practice to guide organisations with staff training and development. Given specialist services in dual disabilities are not widely available, psychologists from a variety of work settings could be supported to advance their skills and expertise via further professional development to assess and treat individuals with an intellectual disability and co-morbid mental health concerns. This will help to ensure that evidence based practices and the quality of service provision for individuals with dual disabilities will not be compromised and continue to be upheld in an ever changing service environment.

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APPENDIX C

Focus Group Questions Used

Please take a few minutes to read through a summary of The Guide.

4. To what extent are these guidelines in line with your current practice:

a) When working with people with an intellectual disability and comorbid mental health concerns in general?

b) When conducting mental health assessments for people with an intellectual disability?

5. In what ways does your current work setting facilitate best practice when working with people with intellectual disability and comorbid mental illness?

6. In what ways does your current work setting hinder best practice when working with people with intellectual disability and comorbid mental illness

Bridging Chapter end of Phase Two

The objective of the second paper from this second phase of research was to investigate organisational factors impacting on evidence based practice implementation in intellectual disabilities. This paper had a particular focus on adherence to an Australian practice guideline aimed at mainstream services working with individuals with dual disabilities. The findings indicated that psychologists' views on best practice were generally consistent with current national best practice standards yet many expressed skepticism regarding its implementation. Organisational factors in relation to organisational level hindrances, the presence and absence of workplace resources and training, operations and the wider service system were reported to both hinder and facilitate best practice implementation. Specifically, organisational values and a work setting which encouraged evidence based practice accompanied by organisational level supports were reported to facilitate best practice for psychologists. In relation to workplace resources, the provision of professional resources and access to experts in dual disabilities was valued by psychologists while the detrimental impact of limited funding on best practice implementation was also highlighted. Working within a collaborative team environment was also noted as facilitative. In relation to hindering factors to best practice, limited expertise and training in intellectual disabilities, unhelpful attitudes towards people with an intellectual disability, collaboration difficulties between health and disability sectors and difficulties accessing mainstream mental health services were reported to impede on best practice in dual disabilities. Given these hindrances, it would be useful to explore the experiences reported by carers in Australia. Specifically, it would be worthwhile to compare the experiences of carers with mental health and disability service settings given that individuals with dual disabilities commonly access both disability and mental health services. Gathering the perspectives of

service users and carers will also shed light on what is considered good practice and allow for the opportunity to offer suggestions on how existing services can be improved.

The results from the first phase of this program of research revealed that psychologists were more confident in identifying mental health symptoms than diagnosing mental health disorders in individuals with an intellectual disability and were more likely to refer on to psychiatrists. This suggests the added complexity of mental health assessments with individuals with an intellectual disability. Carers have a special role to play when assessing an individual with an intellectual disability. Oftentimes, they are the first to recognise a mental health concern and the ones to seek appropriate services for their child with an intellectual disability (Moss et al. 2000). Carers act as informants for their child and are able to provide a history and baseline of the individual's functioning (3DN, 2014). Findings from chapter four revealed that collaboration with carers is a standard practice for psychologists when assessing an individual with intellectual disability. It would be important to examine from a carer's perspective whether they feel included and were consulted during the mental health process in the mental health services sought for their child. Beyond the assessment process, examination of carer and service user experiences with psychology services will also shed light into whether best practices reported by psychologists are reflected in the experiences of those receiving such services.

Taken together, the findings from the first two phases of this research have provided an overview of clinical attitudes and practices of Australian psychologists from a range of clinical backgrounds and work settings and a more detailed account of best practice implementation by psychologists working in government and non-government disability organisations. This has enabled a measure of current reported clinical practices of Australian psychologists in the context of international best practice standards when working with individuals with an intellectual disability and comorbid mental health concerns. What is unknown is how such

services are experienced by carers who are instrumental in seeking these services for their child with an intellectual disability. Accordingly, the overall aim of the third and final phase of this research is to explore the experience of a range of services received by family carers to address mental health and/or challenging behaviour. Services to address challenging behaviour are included in this third phase given the common overlap in behavioural presentations and the fact that challenging behaviour is commonly presented to mainstream mental health services.

Considering the important role of carers in identifying a cause for concern to instigate help seeking for their child (including adult offspring) with an intellectual disability, it would also be useful to examine barriers to help seeking and mental health literacy of carers. Doing so would contribute to our understanding on potential factors impacting on help seeking of appropriate services for individuals with a dual disability. These aims will be addressed in the subsequent Chapters six and seven.

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Chapter 6: Phase 3 Paper 1

Mental Health Literacy, Help Seeking Barriers and Service Satisfaction of Carers of Individuals with Dual Disabilities

Joyce Man & Maria Kangas⁵

Centre for Emotional Health, Macquarie University, Australia

⁵ This is to confirm Joyce Man is the first author and has completed all field work, data analysis and the first full draft of this paper.

Abstract

Background and aim: Carers play an instrumental role in accessing appropriate services for their son or daughter with an intellectual disability with mental health concerns. Carer satisfaction with a variety of services, help seeking barriers and mental health literacy are areas that are not well researched in the intellectual disability field. This paper aims to explore the above with Australian family carers who have an offspring with an intellectual disability with co-morbid mental ill health or challenging behaviour.

Method: Forty two parents took part in an online national survey addressing the nature of services sought for their child/adult offspring with an intellectual disability in the past two years. Twenty seven parents from the full sample completed items on attitudinal barriers to help seeking and completed items based on three vignettes to assess mental health literacy in depression, challenging behaviour and mixed mental health and challenging behaviour presentations.

Results: Carers expressed dissatisfaction with inpatient and community mental health services and rated them as unhelpful. Carers showed good mental health literacy based on responses from the depression and challenging behaviour vignettes and poorer literacy with mixed presentation. Few attitudinal barriers to help seeking were reported by carers.

Conclusions: These findings add to our understanding of service utilisation and satisfaction from a carer perspective and factors impacting on help seeking of services for their offspring with an intellectual disability. Implications for service coordination, provision and carer involvement are discussed.

Introduction

People with an intellectual disability and their families experience barriers in accessing appropriate mental health care. In the international literature, family carers with a son or daughter with an intellectual disability report a number of challenges in getting their needs met with mental health services (Nakamura, Higa-McMillan, Okamura, & Shimabukuro, 2011). For example, in the UK and Canada, families of children and young adults with an intellectual disability who access mainstream inpatient mental health services report many negative experiences and noticeable differences between mainstream and specialist services (Longo & Scior, 2004; Weiss & Lunskey, 2010). On a similar note, interviews with carers in the UK report disempowering experiences during admission to mainstream inpatient units (Donner, Mutter, & Scior, 2010). In particular, some carers found staff were unwilling to assess their adult child with an intellectual disability who were discharged without adequate assessment and attention to their individual needs (Donner et al., 2010). Furthermore, focus groups with parents on their experiences with general practitioners (GP) consultations revealed barriers related to flexibility, access to appointments and dismissal of problems raised by parents (Sayal et al., 2010). Likewise in Australia, Llewellyn, Gething, Kendig, and Cant (2004) interviewed families on their experience with services for their adult child with an intellectual disability. Many frustrations with services were reported such as a lack of recognition of their expertise as parents. These findings suggest the needs of individuals with an intellectual disability and their carers are not being adequately met by existing mental health services, with family carers often feeling devalued in their interactions with professionals.

Beyond hospital and community health settings, government and non-government disability psychological services and private psychiatrists and psychologists also provide services to individuals with co-morbid intellectual disability and mental health concerns. A

study involving focus groups with government and non-government disability psychologists working with individuals with an intellectual disability found that a majority of psychologists held views on best practice that were broadly consistent with national and international practice guidelines for people with dual disabilities (Man & Kangas, 2016) [*Chapter 4*]. Despite this, many barriers to implementing best practice standards were noted, and particularly, difficulties collaborating with mainstream mental health services. Beyond the clinician perspective, little is known of client's experiences with psychological services and whether they match up with psychologists' views on clinical practice. Further investigation would shed light into the nature and quality of currently available psychological services for individuals with an intellectual disability and whether they align with current best practice standards.

Of the existing literature, McGill, Papachristoforou, and Cooper (2006) surveyed family carers of children and young adults with an intellectual disability and challenging behaviour on their satisfaction with formal services and outpatient professional help. Most carers reported dissatisfaction with the level of support and the services received. Of those receiving psychological services, 19% were satisfied while 66% were dissatisfied. The specific reasons for dissatisfaction were not reported; however general feedback on services included the perception of professionals as lacking in understanding in challenging behaviour, and services perceived as uninformative with carers needing to find information themselves (McGill et al, 2006). Such negative experiences with services may have a detrimental impact on a carer's willingness to seek professional help for their child in the future.

Carers play a crucial role and often act as gate-keepers to appropriate services for their child with an intellectual disability. Access to appropriate mental health services requires recognition of the signs of mental health problems, understanding of their significance and knowing who to turn to for help (Moss et al., 2000). Featherstone and Broadhurst (2003)

outline the following three stages as integral to the process of seeking help: problem definition, decision to seek help, and actively seeking help. Given the instrumental role of carers in seeking help for individuals with an intellectual disability, carer perspectives regarding help seeking behaviour is also important to examine.

In the mainstream literature, a study exploring parental help seeking with GPs for their child found that parental embarrassment, stigma of mental health problems, concerns about being labelled or receiving a diagnosis, and concerns about being judged a poor parent were some common barriers to help seeking (Sayal et al., 2010). In the intellectual disability literature, a Canadian study with mothers of children with an intellectual disability found a lack of trust and previous negative experiences with professionals, uncertainty around where to find help, fear of not being taken seriously, uncertainty regarding how to describe the problem and lack of proximity of services dissuaded mothers from seeking help (Weiss & Lunskey, 2010). A further study with adults with an intellectual disability examining factors impacting on the help seeking with GPs found that having someone to talk to about their health and reporting pain in at least one area of their body were significantly associated with a higher number of consultations (Turk, Kerry, Corney, Rowlands & Khattran, 2010). In this latter study, GP consultation rates by individuals with an intellectual disability were also found to be lower than the general population. Collectively, these findings highlight some of the barriers experienced by carers and individuals with an intellectual disability in seeking appropriate mental health care and the impact of carer attitudes on help seeking.

Currently, there is a gap in the literature relating to the experiences of outpatient, community and private services for individuals with intellectual disability and co-morbid mental health conditions. A broader view of carer experiences beyond inpatient mental health services is necessary in order to understand the mental health and disability service system.

Furthermore, to date, no published Australian studies have examined factors impacting on help seeking in carers of individuals with an intellectual disability. Service types, models of care and referral processes may differ across countries, hence further investigation in an Australia context is warranted with the view of improving service access and experiences for carers.

Help seeking with mental health services relates closely to one's ability to recognise a problem and a need for professional attention. Mental health literacy which refers to 'knowledge and beliefs about mental disorders which aid their recognition, management or prevention' (Jorm et al., 1997, p. 182) plays a significant role in help seeking behaviour. In the mainstream literature, a 2006 study by Jorm and colleagues exploring the Australian public's mental health literacy found improvements in recognition of depression and schizophrenia and more positive ratings of a range of interventions, including seeking help from mental health professionals, medications, psychotherapy and psychiatric ward admission compared to findings from the researchers of the original 1995 study (Jorm, Christensen, & Griffiths, 2006a). A more recent study by this group found gender differences in mental health literacy with females exhibiting greater mental health literacy than males on a number of mental health literacy scales (Reavley, Morgan & Jorm, 2014). In particular, in this latter study, exposure to mental illness in having a friend or family member with a problem similar to that described in the vignette was significantly associated with higher mental health literacy (Reavley et al., 2014).

Mental health literacy and the ability of family members to provide reliable information to enable a comprehensive mental health assessment for individuals with intellectual disability are largely unknown. Given the often complex presentations of individuals with an intellectual disability (Costello & Bouras, 2006), and the heterogeneous nature of intellectual disability as a result of varied levels of intellectual functioning, verbal ability, and concurrent diagnoses (such as congenital syndromes medical conditions and physical disabilities), it can be difficult to

distinguish behavioural presentations associated with an intellectual disability from a mental health presentation. In fact, in the field of intellectual disabilities this was observed in support staff in a study by Costello, Bouras, and Davis (2007) which found significant deficits in staff awareness and identification of mental health problems in adults with an intellectual disability. Approximately one-third of individuals with an intellectual disability were incorrectly deemed by staff to be free of mental health problems whose presentations in fact required further clinical attention. Conversely, two thirds of those individuals were wrongly deemed to exhibit psychopathology. Staff were also unable to describe the broad nature of an identified mental health problem in 44% individuals they had identified with a mental health concern. Such findings highlight an overall issue with accurate mental health identification in individuals with an intellectual disability. A lack of accurate and timely identification of mental health concerns by carers can greatly hinder help seeking of appropriate services for individuals with an intellectual disability given their dependency on carers to seek professional help (Moss, Bouras & Holt, 2000).

Mental health clinicians including psychiatrists and psychologists also struggle with mental health diagnosis with the intellectual disability population (Edwards, Lennox & White, 2007; Man, Kangas, Trollor & Sweller, 2016)[*Chapter 2 of dissertation*]. Furthermore, diagnostic overshadowing where mental health presentations of an individual are overshadowed by intellectual disability is a common occurrence amongst mental health clinicians working with individuals with an intellectual disability (Costello & Bouras, 2006; Mason & Scior, 2004). A mainstream study examining mental health literacy in parents of youth diagnosed with mood disorders found that being female, being more educated, having older children, having received more services and having lifetime experience with mental health disorders were predictors of mental health literacy (Mendenhall & Frauenholtz, 2015). A Sri Lankan study examining the

mental health literacy of carers of individuals with depression found 64% carers were able to correctly identify depression, yet 61% also held stigmatising attitudes towards individuals with the mental illness (Ediriweera, Fernando & Pai, 2012). It is not known whether the above findings extend to parent carers of people with an intellectual disability given the limited research literature with this population.

To date, studies on mental health literacy for parents and carers have focused on identification of autism and views regarding appropriate supports and interventions (Koyama et al, 2009; Shyu, Tsai & Tsai, 2010), however, no studies have specifically examined the mental health literacy of carers of individuals with an intellectual disability. Collectively, these studies suggest that diagnostic overshadowing may have a detrimental impact on mental health literacy and that exposure to mental disorders, gender and being recipients of mental health services may impact on mental health literacy in the mainstream population. Given the challenges identified in mental health clinicians and support staff in identifying mental health problems in people with an intellectual disability (e.g., Edwards et al., 2007; Man et al., 2016)[*Chapter 2 of dissertation*] it is possible that family carers may experience similar challenges with mental health literacy. Whether such findings can be generalised to family carers of children and adult offspring with an intellectual disability with exposure to mental health concerns who have received services for their child have yet to be empirically determined. This line of research is crucial in improving identification of the need for mental health services in this population given the instrumental role of carers in seeking services for individuals with an intellectual disability. Accordingly, the objective of this third phase of research was to address this issue.

Aims of the study

The first aim of this study was to investigate parent carers' perspectives on the helpfulness and satisfaction with mental health and/or disability professional services in

addressing their child's mental health/behavioural difficulties. This encompassed behavioural presentations warranting mental health service provision which may or may not have included formal mental health disorder diagnoses. The second aim was to assess carers' mental health literacy in identifying mental health concerns and views on professional help. A third aim was to explore carers' perspectives on barriers to help seeking for their child with an intellectual disability.

Method

Participant Characteristics

Parents with a child diagnosed with an intellectual disability were recruited for an online national survey. Inclusion criteria consisted of parents of children with an intellectual disability of any age who had received services to address challenging behaviour and/or mental health concerns within the past two years in Australia with adequate English literacy. Eligible services included local and community mental health services such as inpatient psychiatric units of local hospitals, local community health teams or via government or non-government disability services. Carers of individuals presenting with challenging behaviour without a formal mental health disorder diagnosis were included in this study given the frequent overlap in presentations and the ongoing complexity associated with assessing the individual.

Forty two parent carers participated in the online survey in which 25 completed the full survey. The majority of carers were female (88%, $n = 37$), whilst the remaining 12% ($n = 5$) were male. Carers' ages ranged between 32 and 75 years ($M = 53.6$, $SD = 9.8$). Children with an intellectual disability were aged between 3 and 40 years ($M = 23.5$, $SD = 8.7$) of which 12 (29%) were 18 years of age or under and 28 (67%) were 19 years or above. Two carers did not provide information of their child's age. This child age cut off was chosen for the analyses in

the current study given individuals aged 18 typically undergo transition from children to adult services in Australia.

Measures

The online survey included demographic information covering the type and purpose of each service received within the past two years, reasons for referrals, and diagnoses of their child. A rating on a five point scale (1=strong agree; 5= strongly disagree) was applied to questions relating to overall satisfaction and helpfulness of each service accessed. The survey included an adapted version of the Barriers to Help Seeking Scale (BHSS-Physical Version) (Mansfield, Addis & Courtenay, 2005) to explore attitudinal barriers to help seeking. Items from the BHSS loaded onto five factors: Factor 1: Need for Control and Self-Reliance, Factor 2: Minimizing Problem and Resignation, Factor 3: Concrete Barriers and Distrust of Caregivers, Factor 4: Privacy and Factor 5: Emotional Control. Eight additional items from the BHSS-Mental health Version were also included to provide a more comprehensive examination of help seeking attitudes. Five of these eight items loaded onto Factor 1, one item loaded onto factor 2 and two items loaded onto factor 3. The vignette at the beginning of the adapted BHSS was also reworded from first person to a child with an intellectual disability given this survey was targeted at parent carers. Two items from the original BHSS-Physical version were omitted as they related specifically to direct physical examinations which were irrelevant to this study. In total, 37 items were included in the adapted BHSS. See appendix D, p. 207 for a full list of items.

Given the BHSS-Physical Version (Mansfield et al., 2005) was adapted to suit the needs of this study, internal consistency of the 37 items was examined. The adapted BHSS showed strong internal consistency with a Cronbach alpha coefficient reported at .97. When adjusted

items were loaded onto the original five factors, items generally showed good internal consistency for factor one at Cronbach alpha .96 (17 items), a Cronbach alpha .82 (6 items) for factor two, .84 for factor three (8 items), .55 (2 items) for factor four (three items from the original BHSS were removed as they did not suit the purposes of this study), and .91 (4 items) for factor 5.

To examine mental health literacy, three vignettes of individuals were presented. The first vignette's presentation was consistent with the criteria for major depression based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) and the Diagnostic Manual-Intellectual Disability (DM-ID) (Fletcher, Loschen, & Stavrakaki, 2000). This vignette was adapted from the study by Jorm and colleagues (1997). A second vignette described an individual presenting with mixed mental health concerns and challenging behaviour in the form of aggressive behaviour while a third vignette presented challenging behaviour associated with a diagnosis of autism. Following presentation of each vignette, participants were asked: a) their view of the problem of the individual, b) how to best help the individual, and c) to rank the helpfulness of a range of options of professional and social supports. These questions were also adapted from Jorm and colleagues (1997). See Appendix E, p. 210 for vignette descriptions.

Procedure

Following institutional ethics approval, participants were recruited via a variety of formats which included: advertising via the first authors networks, the mailing list and newsletter of The Association of Psychologists in Developmental Disability Services (PsychDD), advertisements in the local paper, the Australian Society for Intellectual Disability, and via email to non-government organisations, carer groups and the interest group of the

Australian Psychological Society via online group forums of national disability non-government organisations, advocacy groups and carer groups. Ethics approval was also sought from a local health district to enable the distribution of the study flyer to a number of public health services, some of which included specialist disability health services. Participants were directed to a web link to access the information and consent form. Once online consent was provided, participants were directed to the online survey.

Data analysis

Descriptive and non-parametric Mann-Whitney U tests were used to examine participant characteristics given the small sample did not enable the assumptions of parametric tests to be met. To examine aim one regarding parent carer's ratings of helpfulness and satisfaction with services received in response to their child's mental health/behavioural difficulties, descriptive and non-parametric Mann-Whitney U tests were used. Mann-Whitney U tests were also used to examine differences between carers with children receiving children services with those receiving adult services. To assess the mental health literacy of carers, open-ended responses in relation to perceptions of what was wrong with the individual and how the individual could be best helped were respectively categorised into correct/incorrect and appropriate/inappropriate responses. Given the low sample size which completed the vignettes, descriptive statistics were also used to examine which professionals were rated as most helpful for each vignette.

Descriptive statistics were used to describe barriers to help seeking and the accuracy of carers in correctly identifying the presence of depression, mixed mental health disorder and challenging behaviour and challenging behaviour related to autism from each vignette. To examine the third aim in relation to barriers to help seeking, descriptive statistics were also used. For aims two and three, Mann-Whitney U analyses were conducted to explore differences between carers with

children (less than 19 years) and adult age offspring, and between carer gender and child gender. All analyses had an alpha significance level set at $p < .05$.

Results

Participant Characteristics

Of the 42 participants, 33 (79%) noted their child had at least two diagnoses. Thirty six percent reported their child had a diagnosis of a congenital disorder ($n = 15$), 45% had autism ($n = 19$), 48% reported a mental health disorder ($n = 20$), 5% ($n = 2$) reported some form of challenging behaviour, 41% ($n = 17$) reported other diagnoses such as medical conditions and language disorders (e.g., Epilepsy, Hydrocephalus) and 31% ($n = 13$) reported intellectual disability co-morbid with a mental health disorder. In relation to number of services sought for management of challenging behaviour and/or mental health concerns, 29% ($n = 12$) sought one service in the past two years. Forty three percent sought two to three services ($n = 18$), while 26% ($n = 11$) sought four to six services. The largest proportion of services received were from New South Wales (69%, $n = 29$) with 12% ($n = 5$) from Queensland, 7% ($n = 3$) from Western Australia, 5% ($n = 2$) from Victoria and 5% from Australian Capital Territory ($n = 2$) with none from the Northern Territory and Tasmania. The most frequently sought after service were government or non-government disability services (21.4%, $n = 9$) while public mental health services (hospital inpatient, hospital outpatient or community services) were accessed by 11.9% ($n = 5$) of participants. More than half of the sample sought a mixture of service types (54.8%, $n = 23$). Of the professionals sought, psychiatrists were seen the most often with 38% ($n = 16$) seeking a psychiatrist at least once for their child with an intellectual disability. Psychologists were similarly sought after with 36% ($n = 15$) seeking psychological services at least once. In terms of nature of service, intervention services were the most frequently sought after with 60% ($n = 25$) seeking this at least once. Assessment services were similarly sought after with 57% ($n = 24$) seeking this at least once.

= 24) receiving this service at least once. See Table 1 for frequencies on types of services and professionals sought and nature of service received.

Table 1

Sample Demographic Characteristics

	Full sample		Carers with children 18 years or under		Carers with offspring 19 years or older	
	<i>N</i>	% total sample	<i>n</i>	% total sample	<i>n</i>	% total sample
Service type sought	42	100	11	100	28	100
Government and non-government disability services only	9	21.4	0	0	9	32.1
Hospital inpatient, outpatient and community services only	5	11.0	2	18.2	3	10.7
Specialist services only	1	2.4	0	0	1	3.6
Mixture of services	23	54.8	7	63.6	14	50
Other	3	7.1	2	18.2	1	3.6
Professionals sought	42	100	12	100	28	100
Psychiatrist	16	38.1	3	25	12	42.9
Psychiatric registrar	5	11.9	3	25	2	7.1
Nurse	6	14.3	3	25	3	10.7
Psychologist	15	35.7	3	25	11	39.3
Clinical psychologist	8	19	2	16.7	6	21.4
Specialist Psychologist	2	4.8	1	8.3	1	3.6
Behaviour support practitioner	6	14.3	2	16.7	3	10.7
Other	16	38.1	5	41.7	9	32.1
Nature of service	42	100	12	100	28	100
Assessment	24	57.1	6	50.0	17	60.7
Intervention	25	59.5	6	50.0	18	64.3

	Full sample		Carers with children 18 years or under		Carers with offspring 19 years or older	
	<i>N</i>	% total sample	<i>n</i>		<i>N</i>	% total sample
Parent training/support	15	35.7	4	33.3	11	39.3
Clinic/consultation	17	40.5	5	41.7	12	42.9
Crisis mental health management	9	21.4	3	25.0	5	17.9
Medical review	13	31.0	4	33.3	9	32.1
Other	6	14.3	0	0	6	21.4

Carers with children 19 years old or older ($Md = 57$, $n = 28$) were significantly older than carers with children 18 years or younger ($Md = 47$, $n = 12$) $U = 61.5$, $z = -3.15$, $p = .002$, $r = .50$. No other differences in demographic variables were found between these two carer groups ($p > .05$). Sixty two percent had a son with an intellectual disability ($n = 26$) while 38 % ($n = 16$) had a daughter with an intellectual disability.

Sixty four percent of the full sample ($n = 27$) completed items from the BHSS and mental health literacy vignettes. To compare the characteristics of carers from the full sample whom did not complete the BHSS and mental health literacy items with carers who did, Mann-Whitney U tests were conducted. Carers in the BHSS and mental health literacy sub-sample sought more services involving assessment, intervention, parent training and support, clinic/consultations, crisis mental health service and medical reviews than carers who did not complete the BHSS and mental health literacy sections. This sub-group also sought more services from psychiatrists, psychologists, clinical psychologists than carers who did not complete the full survey. See Table 2 for Mann-Whitney U statistics. Within this sub-sample, 6 (22%) had a child 18 years or younger with an intellectual disability, 20 (74%) had an adult offspring 19 years of age or over, and one carer did not provide information about their child's age. From this sub-sample, thirteen (48%) reported their child had a mental health disorder, 12 (44%) had autism, 9 (33%) had a congenital disorder

while 9 (33%) had an intellectual disability with a co-morbid mental health disorder, one had challenging behaviour (4%) while 12 (44%) noted other diagnoses such as medical conditions and language disorders.

Table 2

Comparisons between Carers Completing BHSS and Mental Health Literacy items and Carers who Did Not

	Mean ranking of sample completing BHSS and Mental health literacy items (<i>n</i> = 27)	Mean ranking of sample <i>not</i> completing BHSS and Mental health literacy items (<i>n</i> = 15)	Mann- Whitney U	<i>P</i> value	Effect size <i>r</i>
Nature of service					
Assessment	27.61	10.5	37.50	.000	.71
Intervention	27.30	11.07	46.00	.000	.67
Parent training and support	25.67	14.0	90.00	.001	.53
Clinic/consultation	26.22	13.0	75.00	.000	.58
Crisis mental health management	24.00	17.0	135.00	.013	.38
Medical review	25.11	15.0	105.00	.013	.48
Professional sought					
Psychiatrist	24.06	16.9	133.50	.037	.32
Psychologist	25.67	14.0	90.00	.001	.53
Clinical psychologist	23.72	17.5	142.50	.021	.36

Helpfulness and Satisfaction with Services

Results revealed that carers with children 18 years or under ($Md = 1, n = 6$) (receiving children services) reported more satisfaction with non-government disability services than carers with children 19 years or over (receiving adult services) ($Md = 2.5, n = 18$), $U = 21, z = -2.34, p = .019, r = .48$. No other differences in helpfulness and satisfaction ratings across services were found between these two groups of carers ($p > .05$).

Overall, hospital inpatient and community mental health services were viewed as the least helpful while specialist services were reported as the most helpful. Helpfulness ratings towards non-government services were mixed with 32% ($n = 9$) rating the service as helpful while 29% ($n = 8$) found it unhelpful. Hospital outpatient helpfulness ratings were similarly mixed with 18% ($n = 5$) reporting the service was helpful while 25% ($n = 7$) found the service unhelpful. Psychology helpfulness ratings were similarly mixed with 32% ($n = 9$) stating the service as helpful while 25% ($n = 7$) stating it as unhelpful. See Table 3 for a full list of helpfulness and satisfaction ratings.

In regards to satisfaction ratings, hospital inpatient and community mental health services were rated as the least satisfactory while psychological services were reported as the most satisfactory of the services received. Findings on satisfaction of services were mixed for non-government disability services with 32% ($n = 9$) disagreeing or strongly disagreeing that they found services satisfactory, while 29% ($n = 8$) agreed or strongly agreed that they found the service satisfactory. Ratings of satisfaction regarding hospital outpatient services were similarly divided with 25% ($n = 7$) finding the service satisfactory while 29% ($n = 8$) found it dissatisfactory. See Table 3 for details.

Table 3

Helpfulness and Satisfaction Ratings with Services

Type of service	Helpfulness Rating			Satisfaction rating		
	Mean (SD)			Mean (SD)		
	Full sample (<i>N</i> = 42)	Carers with children 18 years or under (<i>n</i> = 12)	Carers with offspring 19 years or older (<i>n</i> = 28)	Full sample (<i>N</i> = 42)	Carers with children 18 years or under (<i>n</i> = 12)	Carers with offspring 19 years or older (<i>n</i> = 28)
Specialist services	1.74 (.92)	1.40(.89)	1.94(.93)	1.84(.94)	1.33(.82)	2.12 (.93)
Non-government disability	1.91 (.90)	1.83 (.75)	1.94 (.97)	2.04 (.86)	1.33 (.52)	2.24 (.83)
Hospital outpatient	2.13 (.92)	1.50 (1)	2.30 (.82)	2.06 (1.0)	1.50 (1)	2.18 (.98)
Psychology	1.89 (.92)	2.00 (1.15)	1.93 (.92)	1.69(.87)	1.50 (1)	1.76 (.83)
Government Disability	2.38 (.80)	1.80 (.84)	1.94 (.97)	2.39 (.84)	1.83 (.98)	2.67 (.62)
Hospital inpatient	2.45(.69)	2.25 (.96)	2.57 (.53)	2.43(.76)	2.00 (1)	2.67 (.50)
Community	2.42(.77)	2.20 (1.10)	2.46 (.66)	2.43(.68)	2.33 (1.03)	2.43 (.51)

Mental health literacy of carers

In relation to the vignette depicting an individual with depression, 64% of the full sample completed mental health literacy items for this scenario (*n* = 27). Seventy four percent (*n* = 20) of carers were able to correctly identify that the individual was experiencing low mood, adjustment, grief issues or depression as a result of the loss of a friend. Incorrect responses included changes to the individual's routine, loneliness and general statements about a

situational change. Carers with a son with an intellectual disability (*Mean rank* = 15.91, *n* = 17), were better at identifying depression compared to carers with a daughter with an intellectual disability (*Mean rank* = 10.75, *n* = 10), $U = 52.5$, $z = -2.15$, $p = .032$, $r = .41$.

When asked how this individual could be best helped, a majority of carers (96%, *n* = 26) suggested appropriate responses to the individual's concern. Some examples included consulting with a GP, accessing psychological services, counselling and seeking social support and engagement for the individual. Mothers reported more appropriate responses to depression ($M = 1$, $SD = 0$, *n* = 23) than fathers ($M = 0.75$, $SD = 0.5$, *n* = 4). Carers were asked to rank the helpfulness of a range of follow up supports which consisted of professional, social and spiritual support. Carers rated family support as the most popular form of help, rated in the top three most helpful by 78% (*n* = 21) of carers. GPs were second popular, rated in the top three by 56% (*n* = 15) of carers. Case managers were ranked in the top three by 48% (*n* = 13) of carers. See Table 4 for a full ranking list.

For the second vignette depicting an individual with mixed challenging behaviour and mental health concerns, 60% (*n* = 25) of the full sample completed items related to this vignette. Six parents (25%) had children 18 years of age or younger while 18 had adult offspring 19 years or older (72%). Forty percent of participating carers (*n* = 10) were able to correctly identify some form of challenging behaviour and/or mental health condition in relation to her interactions within the day program. Correct responses made reference to a mental health condition such as anxiety or depression, change in mood and/or behavioural problems. Incorrect responses were made by 60% of the sub-sample where no direct evidence was found within the content of the vignette. Some examples of incorrect responses included trauma, bullying in the workplace, problems at home and being sexually assaulted. A majority of carers

(84%, $n = 21$) provided appropriate suggestions on ways to help the individual in response to their identified concern.

Table 4

Suggested Help Seeking in Response to Mental Health Literacy Vignettes

	Depression		Mixed challenging behaviour and mental health disorder		Challenging behaviour with autism	
Type of help rated within the top three most helpful	<i>n</i>	% total sample	<i>n</i>	% total sample	<i>n</i>	% total sample
GP	15	56	11	44	9	36
Psychiatrist	5	19	7	28	4	16
Psychologist	7	26	8	32	7	28
Case manager/social worker	13	48	14	56	17	68
Occupational therapist	0	0	0	0	1	4
Speech Pathologist	0	0	1	4	2	8
Counsellor	6	22	5	20	3	12
Behaviour support practitioner	6	22	10	40	13	52
Family	21	78	17	68	16	64
Other social support	5	19	2	8	3	12
Religious clergy	1	2	0	0	0	0
Other	2	7	0	0	0	0

Some examples included seeking counselling, environmental supports in the day program and further assessment to understand the cause of the individual's distress. Inappropriate responses included removing the individual or the individual who was the target of hair

pulling from the day program. Family support was ranked as the most helpful form of support with 68% ($n = 17$) ranking it in the top three. Case management services were popular with 56% ($n = 14$) ranking this within the top three while seeking a GP was rated in the top three by 44% ($n = 11$) of carers.

For the third and final vignette, 60% ($n = 25$) of the full sample completed items relating to the scenario which depicted challenging behaviour associated with a diagnosis of autism. Again, six parents (25%) had children 18 years of age or younger while 18 had adult offspring 19 years or older (72%). Eighty four percent of the sample ($n = 21$) who completed this section were able to correctly identify the individual's fixation with cars and/or its relation to autism. Incorrect responses included boredom, a lack of engagement with creative activities and Obsessive Compulsive Disorder. Seventy six percent of carers ($n = 19$) were able to offer responses/management strategies that were considered appropriate such as seeking behavioural intervention, finding an appropriate outlet for the individuals' fixations with cars and expanding on his interests. Inappropriate responses included moving the individual to supported accommodation, encouraging the individual to continue to feed his interest in cars without mention of any limit setting. Carers rated case management services as the most helpful with 68% ($n = 17$) ranking this within the top three. Family support was also popular, ranking in the top three by 64% ($n = 16$) of carers. Consulting behaviour support practitioners was ranked in the top three most helpful by 52% ($n = 13$) of carers. Overall, no differences in mental health literacy was found between carers with children 18 years or younger and carers with adult offspring (19 years or above) across any of the three vignettes (all $ps > .05$).

Barriers to Help Seeking

To investigate the third aim, 27 carers (64% of the full sample) completed the adapted BHSS (Mansfield et al., 2005). Overall, carers reported few barriers to help seeking. Carers reported low scores on all five factors of the BHSS (see Table 5 for details) indicating that all five help seeking domains were not considered significant barriers to seeking help for their child with intellectual disability.

Table 5

Barriers to Help Seeking Scale Total and Factor Scores (N = 27)

BHSS factor	<i>M</i>	<i>SD</i>	Minimum score	Maximum score
BHSS total score	57.0	24.6	37	185
Factor 1: Need for control and self-reliance	24.3	11.8	17	85
Factor 2: Minimising problem and resignation	9.3	4.0	6	30
Factor 3: Concrete barriers and distrust of caregivers	14.1	6.8	8	40
Factor 4: Privacy	2.6	1.1	2	10
Factor 5: Emotional control	5.5	3.1	4	20

Note. The higher the factor score, the more this factor was considered a barrier to help seeking

Out of the five factors, concrete barriers and distrust of caregiver scores were rated the highest on average while emotional control scores were the lowest on average. This suggests that “finances, lack of insurance, lack of transportation, lack of knowledge about the sorts of help available, and lack of trust in care providers” were the biggest barrier to help seeking while attitudes in relation to “keeping one’s emotions under control and out of public view” (Mansfield et al., 2005, p. 105) was considered the smallest barrier to help seeking. Given the small sample size, these findings need to be interpreted with caution given parametric statistical

analyses were unable to be completed. Overall, no differences in BHSS total and factor scores were found between carers with children 18 years or younger and carers with adult offspring (19 years or above) ($p > .05$). Also no gender differences in carers or in individuals with an intellectual disability were found with BHSS scores.

Discussion

Findings from this study revealed that family carers held varying views towards mainstream disability and mental health services and viewed themselves as playing an important role in recognising and supporting mental health concerns for their child with an intellectual disability. The findings for aim one of this study revealed that hospital inpatient and community mental health services were rated as unhelpful and unsatisfactory on average by carers who had sought these services. It is possible that carers with these services did not experience the level of expertise in dual disabilities in comparison with specialist services which were rated as most helpful. Hospital inpatient settings are typically under resourced and may have less flexibility in adjusting their usual practice to suit the needs of individuals with an intellectual disability (Ali et al., 2013) despite the higher use of inpatient services by individuals with an intellectual disability compared with the general population in NSW (Department of Families and Community Services NSW, 2012). A previous Australian data linkage study also revealed that people with an intellectual disability had more contact and used more service time than people without an intellectual disability in mainstream hospital settings (Howlett, Florio, Xu, & Trollor, 2014), suggesting the complex service needs of this specialist population. Carers with children 18 years or younger primarily accessing children services were also found to be more satisfied with non-government disability services than carers with adult offspring accessing mostly adult services. It is possible that this may be a reflection of the differences in the types and formats of service provision available by non-government services for children compared with adult non-

government services. The former may involve early intervention therapy and family support while the latter may involve more recreational, occupational and skills based training for individuals with an intellectual disability with less emphasis on family support. Indeed, there is a focus on family-centred practices in services for children with a disability (Dempsey & Keen, 2008).

In relation to aim two which explored the mental health literacy of carers, carers in general showed relatively good awareness of depressive symptoms and challenging behaviour associated with autism. In particular, carers of individuals with dual disabilities possessed high mental health literacy with depression (74% correct responses). This contrasts with a study with the general population by Jorm et al. (2000) where only 59% of participants correctly identified depression. One reason for this difference may be related to mental health disorder exposure where almost half of participating carers' children/adult offspring had a mental health condition while 32% had a dual disability. As a result, more carer exposure to mental health conditions in their offspring may have contributed to better awareness of signs of mental illness in comparison to the general population. In fact, carers who completed the mental health literacy items in this study had more exposure to a range of services as well as with psychiatrists, psychologists and clinical psychologists compared with carers who did not complete this section. Consistent with these findings, in a previous Australian-based community sample, having a friend or family member or having worked with people with depression were significantly associated with better mental health literacy for depression (Reavley, Morgan and Jorm, 2014). Moreover, in the current study, it was interesting to find that carers with a son with an intellectual disability were better at identifying depression compared to those with a daughter with an intellectual disability. It is unclear why this was the case given no differences between number of services sought and mental health diagnoses were found between sons and

daughters with intellectual disability with this sub-sample. Thus, the finding cannot be explained by increased exposure to mental health disorders nor additional complexity as suggested by a higher number of services sought. Mothers were also found to be better at suggesting appropriate responses to depression than fathers. This latter outcome is consistent with findings from a study with parents of children with mood disorders where female caregivers displayed more knowledge about mental health treatment for mood disorders than their male counterparts (Mendenhall & Frauenholtz, 2015). However, these findings need to be interpreted with caution given the small sample size. In addition, more information around other forms of carer exposure to mental health concerns (e.g. via own personal experience) and a larger sample would provide more depth into examinations of mental health literacy as well as to replicate the findings from this study.

In relation to mental health literacy with autism, a majority of carers (84%) were able to correctly identify challenging behaviour and/or its association with autism. This contrasts with a study with the Japanese general population where 46% of participants correctly identified autism from a vignette (Koyama et al., 2008). Again, it is possible that exposure to autism may have contributed to higher prevalence of mental health literacy of carers in the current sample, given 44% of the sample reported their child/adult offspring had autism. Despite the complex presentations of individuals with an intellectual disability and co-occurring mental health concerns, it is encouraging to find that carers are often sensitive and aware of changes in their child's typical functioning that cannot be explained by their intellectual disability alone. Similar high rates of mental health literacy were also found in a mainstream study with foster carers where 86% of foster carers correctly identified a range of child mental health disorders using vignettes (Bonfield, Collins, Guishard-Pine & Langdon, 2009).

In relation to the vignette depicting mixed mental health and challenging behaviour, the relatively low literacy of carers (40% correct responses) may be a reflection of the added difficulties in identifying individuals with dual disabilities who have complex presentations in real life circumstances. This possibility is supported by findings from a previous Australian data linkage study which examined the service utilisation patterns of individuals with an intellectual disability with mainstream mental health services (Howlett et al., 2014). It was found that individuals with an intellectual disability were more than twice as likely to have an ‘unknown’ diagnosis compared to the general population (Howlett et al., 2014). Hence, the challenge of mental health identification in individuals presenting with a number of diagnostic co-morbidities appears to be experienced by both carers and mental health professionals as suggested by findings from this study and the previous citation.

Overall, carers were able to identify responses to the individuals’ presenting problems that were deemed appropriate for the vignettes presented for depression and for challenging behaviour related to autism. Interestingly, family support was considered the most popular form of support in response to each of the three vignettes’ presenting issue. However, it should be noted that there was some overlap between the three vignettes regarding presentation of a mental health condition with mental health presentations appearing in both the first and second vignette while challenging behaviour was depicted in both the second and third vignette. Based on these findings it seems that many carers viewed their role as crucial in assisting the individual to seek support and initiate assessment for the individual. This further reinforces the pivotal role carers play in the care and well-being of individuals with dual disabilities.

In this study, GPs were also highly regarded as a source of help in response to mental health and challenging behaviour. This is not surprising given their role as gatekeepers to a range of support services in Australia. This finding is also consistent with an Australian study

by Jorm, Christensen and Griffiths (2006a) where the general population viewed GP and family support as the most helpful responses to depression. Similarly, a study with carers of individuals with mental health disorders rated psychiatrists, GPs, and support from close family and friends as the most helpful responses to depression management (Ediriweera et al., 2012). Moreover, in Australia, GPs may be seen as the initial source for assessment for the individual and the profession most able to make referrals to appropriate services. In particular, a GP referral is required in Australia in order to receive Medicare (government paid) rebates from private psychiatrists and psychologists and to access public specialist clinics. Similarly, in this study, case management services were also viewed as instrumental as a referral source for additional services. Family support and case management services were seen as important for all three scenarios, suggesting the crucial nature of their roles in response to presentation of challenging behaviour and/or mental health problems of the individual with an intellectual disability.

A third aim of this study was to investigate attitudinal barriers of carers to seeking help for their child with dual disabilities. It was interesting to note that there were few barriers to help seeking as identified by the adapted BHSS (Mansfield et al., 2005). Barriers related to a need for control and self-reliance, minimising problem and resignation, practical barriers and distrust of service providers, privacy and emotional control did not appear to substantially hinder help seeking for their child with intellectual disability. However, out of all five factors, the factor Concrete Barriers and Distrust of Caregivers was considered the biggest barrier. This related to practical barriers and distrust of service providers. It is possible that with a larger sample, this may have rendered significant findings. This is consistent with findings from qualitative studies on the experience of carers of individuals with an intellectual disability with mental health services where barriers involved practical barriers and distrust of paid caregivers

(e.g., Nakamura et al., 2011; Sayal et al, 2010). One reason for this may be the often pervasive nature of service involvement for their child with an intellectual disability. However, although in the current study participants were asked about the type of services involved in the care of the individual with intellectual disability within the past two years, the duration of engagement with each service is unknown.

A majority of carers (69%) in this study had sought two or more services for their child with an intellectual disability and co-morbid mental health concerns and/or challenging behaviour. Receiving some form of support on a regular basis is often typical whether this is respite, medical reviews, therapy services or other support services. Given a larger proportion of carers who completed this study had adult offspring, such parents would have accumulated many years of experience in seeking and dealing with a range of support services. On a similar note, a study with foster carers of children without intellectual disabilities reported many positive attitudes towards seeking psychological help which significantly impact on help-seeking of children mental health services (Bonfield et al., 2009). This was also found with a British community sample where negative attitudes toward seeking psychological and psychiatric help and greater anti-scientific attitudes predicted lower likelihood of respondents recommending help for depression (Swami, 2012). It should be noted that one key inclusion criteria for this current study involved carers having accessed some form of service for their child with an intellectual disability. It is likely that more barriers to help seeking may be identified in carers who have never or seldom sought services for their child with an intellectual disability. However, it was beyond the scope of this study to formally investigate this and therefore should be a focus for further research.

Study Strengths and Limitations

The findings from this study need to be understood in context of a number of limitations. Firstly, the small sample size heavily impacts on the generalisability of the findings. The small representations of carers with children with an intellectual disability accessing children services (18 years of age or below) and adult services (19 years of age and above) also imposed limitations on statistical methodology available to explore the aims of the study. Despite the extensive time and effort invested in recruitment from a wide variety of avenues across mental health, health and disability services across Australia, the small sample was disappointing but not necessarily surprising. Although many services and carers expressed interest in participating in the study, carers were typically time poor and their child with dual disabilities may have been experiencing ongoing or recurrent difficulties as a result of challenging behaviour and/or mental health conditions. This is comparable to other quantitative studies completed with carers of individuals with an intellectual disability involving small sample sizes (e.g., Hill & Rose, 2009; Llewellyn, McConnell, & Bye, 1998; McGill, Papachristoforou & Cooper, 2006). Furthermore, given the self report nature of the study, the diagnoses of individuals with an intellectual disability reported by participating carers are informal only. No evidence of formal diagnoses of individuals with an intellectual disability was sought. Although the survey asked for the professional involved in the child's diagnosis, this information was not always completed and was dependent on accurate reporting by carers of diagnoses where some may have been provided in the early developmental years (e.g., autism, epilepsy and intellectual disability).

In addition, although families from culturally and linguistically diverse backgrounds were also targeted, carers recruited for this study from non-English backgrounds often did not have adequate English ability to complete the study. It is possible also that parents who chose

to participate had strong impressions of the services they have received for their child. Such impressions are likely to skew the study's findings, particularly in relation to ratings of helpfulness and satisfaction with services and therefore may not be an accurate representation of carer experiences overall. Although information was not sought on the cultural background of individuals, it is likely that there was an overrepresentation of carers from Caucasian/English speaking backgrounds who were more informed about disability services. Furthermore, it was beyond the scope of this study to explore in more detail the reasons for such ratings on helpfulness and satisfaction with each service received.

Despite the above mentioned limitations, this study is the first to explore mental health literacy with carers of individuals with intellectual disability. Given the instrumental role carers play in instigating services for their child with intellectual disability, such investigations contribute to our understanding of how well equipped they are in recognising signs of mental health concerns that warrant further attention. This is also one of the few studies to formally explore barriers to help seeking for carers with an intellectual disability. The use of the adapted BHSS (Mansfield et al., 2005) also allows for exploration of specific attitudinal barriers to seeking help. In doing so, this provides a better understanding of how to best support carers so that specific attitudinal barriers impeding on their willingness to seek mental health services for their child with an intellectual disability can be addressed. Specifically, to combat concrete barriers to help seeking, improved knowledge and accessibility of services would assist to empower carers to seek appropriate services for their child with intellectual disability. In addition, attitudes associated with distrust of paid caregivers need to be combated with collaborative working relationships and person centred practices that not only value the individual with an intellectual disability, but the important role of carers in the lives of their child.

Study Implications

Findings from this study suggest carers often seek multiple services for their child with dual disabilities. The fact that psychiatric and psychological services were sought the most often by carers has implications for service access and development. Furthermore, given that both government and non-government disability services were the most frequently sought after by carers for their child's challenging behaviours and mental health concerns, and that the nature of services most commonly involved assessment and intervention, care must be taken to ensure such services are in line with international best practice standards. It is noteworthy that a majority of participants (69%) sought more than one service for their child, which suggests the complex needs of the individual with an intellectual disability. Multiple services also highlight the importance of a systemic approach involving inter disciplinary and inter service collaboration in order to create the best outcomes for individuals with dual disabilities and their families (Trollor, 2014). Smooth coordination between services with unified general objectives across services is likely to improve the experiences of individuals with dual disabilities and their carers. Given that hospital inpatient and community health services received the lowest ratings on helpfulness and satisfaction from carers, more attention needs to be drawn to improving the accessibility of these services to individuals with an intellectual disability and their families. Future research into the experiences of carers with mainstream mental health services is recommended to determine reasons for such low ratings. This would assist in guiding how these services can be improved in order to better meet the needs of individuals with dual disabilities and their families.

Given relatively good mental health literacy regarding depression and challenging behaviour associated with autism presentations reported by carers, it is recommended that carers be better supported to access appropriate services and included in the assessment process as key

informants of the individual with an intellectual disability. Carers possess invaluable knowledge about their child with an intellectual disability and are in a good position to provide information on the mental health, behavioural and family history and change in baseline functioning of the individual with an intellectual disability. Based on the findings from this study, they also view themselves as holding a key role in response to the presenting issues depicted in the three mental health literacy vignettes. Thus, service providers should make efforts to involve carers in treatment decision making to maximise mental health outcomes for individuals across the lifespan with an intellectual disability.

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APPENDIX D

BHSS- Adapted version

There are a variety of reasons why people choose to seek help or not seek help from doctors, psychiatrists, psychologists or other mental health professionals. We're interested in the sorts of reasons why you might choose **not** to seek help for your adult child with an intellectual disability for a particular problem.

Imagine your child begins to experience episodes of anxiety or depression that last more than a little while. Every day he/she is feeling either very anxious, very down, or lacking interest in things he/she used to enjoy. In addition, you begin to notice your child has difficulty sleeping, is often tearful, has changes in his/her appetite, or an overall increase in levels of stress and agitation. Imagine that these changes continue most of the time for at least two weeks.

How likely would you be to seek help for the above problem for your child from a mental health professional? Circle a number.

Not at all likely 1	2	3	Somewhat likely 4	5	6	Extremely likely 7
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Continue to imagine yourself in the situation described above, and respond to each reason why you might choose NOT to seek help for the problem for your child. Please read each reason and rate it according to how much it would be a reason that YOU as a carer to not seek help. Please circle a number on the scale to indicate your answer.

Below are some reasons why you might not seek help. **Please read each reason and decide how important it is in keeping you from seeking help for your child.** If you think that a reason is very important in keeping you from seeking help, you should circle a 4. If you think that a reason is not at all important, you should circle a zero. You can also circle any number in between to indicate how important a reason is for not seeking help.

Not at all a reason 0	1	2	3	Very important reason 4
-----------------------------	---	---	---	-------------------------------

- | | | | | | |
|--|---|---|---|---|---|
| 1. I would think less of myself for needing help. | 0 | 1 | 2 | 3 | 4 |
| 2. The problem wouldn't seem worth getting help for. | 0 | 1 | 2 | 3 | 4 |
| 3. People typically expect something in return when they provide help. | 0 | 1 | 2 | 3 | 4 |

4. Privacy is important to me, and I don't want other people to know about my child's/family's problems.	0	1	2	3	4
5. I don't like to get emotional about things.	0	1	2	3	4
6. I don't like other people telling me what to do.	0	1	2	3	4
7. The problem wouldn't be a big deal; it would go away in time.	0	1	2	3	4
8. I would have real difficulty finding transportation to a place where I can get help.	0	1	2	3	4
9. This problem is embarrassing.	0	1	2	3	4
. 10. I don't like to talk about feelings.	0	1	2	3	4
. 11. Nobody knows more about my problems than I do.	0	1	2	3	4
. 12. I wouldn't want to overreact to a problem that wasn't serious.	0	1	2	3	4
13. I wouldn't know what sort of help was available.	0	1	2	3	4
14. Most "professionals" don't really know what they're talking about.	0	1	2	3	4
15. I'd rather not show people what I'm feeling.	0	1	2	3	4
16. I'd feel better about myself knowing I didn't need help from others.	0	1	2	3	4
17. Problems like this are part of life; they're just something you have to deal with.	0	1	2	3	4
18. Financial difficulties would be an obstacle to getting help.	0	1	2	3	4
19. It's important to me to make my own decisions and not be too influenced by others.	0	1	2	3	4
20. I wouldn't want to look stupid for not knowing how to figure this problem out.	0	1	2	3	4
. 21. I don't like feeling controlled by other people.	0	1	2	3	4
22. I'd prefer just to suck it up rather than dwell on my problems.	0	1	2	3	4
23. I don't trust doctors and other health professionals.	0	1	2	3	4
24. I wouldn't have time to get help.	0	1	2	3	4

25. It would seem weak to ask for help.	0	1	2	3	4
26. I would prefer to wait until I'm sure the problem is a serious one.	0	1	2	3	4
27. A lack of health insurance would keep me from seeking help.	0	1	2	3	4
28. I like to make my own decisions and not be too influenced by others.	0	1	2	3	4
29. I like to be in charge of everything in my life.	0	1	2	3	4
30. Asking for help is like surrendering authority over my life.	0	1	2	3	4
31. I do not want to appear weaker than my peers.	0	1	2	3	4
32. I wouldn't know what sort of help was available.	0	1	2	3	4
33. When it comes right down to it, it's my problem and I have to solve it myself.	0	1	2	3	4
34. I should be able to handle this on my own.	0	1	2	3	4
35. The problem makes me feel like less of a parent.	0	1	2	3	4
36. I wouldn't feel confident that I would be helped.	0	1	2	3	4
37. I've asked for help before and it was a waste of time.	0	1	2	3	4

APPENDIX E

Mental health Literacy Vignettes and Question items

1. Depression vignette

Michael is 26 years old and attends supported employment three times a week. Michael has been working at the same place for three years and gets along well with his supervisors and co-workers. He usually likes to greet everyone upon his arrival and likes to share jokes with others. Lately his supervisor has noticed that Michael is no longer his usual outgoing self. He appears flat, lethargic and no longer jokes with others. He will sit at his work station and stare blankly into space and may become teary at times. Upon arrival to work, Michael will stay in the kitchen area by himself and no longer greets others in the morning. When asked what is wrong, Michael asks 'Where's Danny?' Danny and Michael were close friends and co-workers. Danny's family moved out of area a few weeks ago and no longer works at the centre.

2. Mixed challenging behaviour and mental health disorder vignette

Jenny is a 35 year old lady. She attends a day program where she engages in leisure and independent living skills training three times a week. Jenny's favourite activity is cooking which she looks forward to participating in once a week at the program. For the most part, Jenny is a friendly and gentle individual. Lately, day program staff have noticed Jenny becoming upset by others easily and will push staff away if they try and encourage her to participate in the program's activities. Jenny has also started pacing around the centre and will scream out loud for no apparent reason. Jenny no longer wants to engage in her favourite cooking activity and staff are finding it increasingly difficult to motivate Jenny to participate at all in the centre's activities. Jenny has also developed a dislike for one of the clients at the centre and will find opportunities to pull her hair when staff aren't looking.

3. Challenging behaviour associated with autism vignette

Tim is 47 years old and lives at home with his elderly parents and younger brother. Tim has a strong interest in cars and will spend all day sitting out the front porch counting cars if there are no scheduled outings with respite on the day. It takes Tim's parents a lot of nagging and yelling to get Tim inside the house which he will only do during meal times and when it starts to get dark outside. Once inside the house, Tim will continue to talk about cars, their colours, models and will repeatedly ask when he can go for a car ride. It is very difficult for Tim's family to get Tim to talk about anything else besides cars.

For each case:

1. In a few words, what do you think is wrong with the individual?
2. How do you think the individual can be best helped?

3. Please rank the helpfulness of the below in addressing the individual's problem (note all professionals specialise in intellectual disabilities)
- GP
 - Psychiatrist
 - Psychologist
 - Case manager/social worker
 - Occupational therapist
 - Speech Pathologist
 - Counsellor
 - Behaviour support practitioner
 - Family
 - Other social support
 - Religious clergy
 - Other. Please specify_____

Bridging Chapter following Chapter 6

The first paper arising from Phase three of this research focused on investigating carer views on helpfulness and satisfaction with services received for their child/adult offspring with an intellectual disability' mental health concerns and/or challenging behaviours. This paper also focused on carer mental health literacy in identifying depression, challenging behaviour and mixed presentations as well as attitudinal barriers to help seeking. Outcomes from this paper revealed carers showed good literacy when it came to identifying depression, challenging behaviour associated with autism and showed good understanding of appropriate forms of formal and informal supports. Less carer literacy was found in identifying mixed challenging behaviour and mental ill health which compares with difficulties reported by psychologists in phase one and two regarding mental health diagnosis with individuals with an intellectual disability.

Carers also reported limited attitudinal barriers regarding help seeking. However, logistical barriers and distrust of services were considered the biggest barrier. The subsequent qualitative paper involves interviews with family carers to allow for a more detailed exploration of whether such barriers are experienced by carers in their quest to find appropriate mental health care for their child with dual disabilities. This draws parallels with findings from phase two which revealed barriers to best practice in the form of inter agency collaboration and access to mental health services difficulties for individuals with an intellectual disability as reported by psychologists in the disability sector.

Carers also reported dissatisfaction and ratings of unhelpfulness with inpatient and community mental health services. It is beyond the scope of this paper to explore reasons for these negative ratings. The last paper of this research delves deeper into carer experiences with

mainstream mental health services accessed in response to mental health concerns of their child with an intellectual disability. Findings from the subsequent paper contribute to our understanding of mental health literacy in action in relation to how mental health concerns are identified by the carer and their subsequent journey in seeking access to appropriate services. Given few attitudinal barriers to help seeking were found in the previous paper, it would be important to explore whether additional barriers in help seeking exist for carers.

Hence, the concluding paper aimed to explore family carer experiences with mainstream mental health services, in particular experiences during the assessment process as well as experiences of psychological services. Carer perspectives on ways to improve services were also sought. This provided a broader picture regarding the experiences of carers in parallel with clinical practices and views reported by psychologists in phase one and two of this thesis.

Chapter 7: PHASE 3 PAPER 2

Carer Experiences of Services for adults with Intellectual Disabilities and Co-morbid Mental ill Health or Challenging Behaviour

Joyce Man & Maria Kangas⁶

Centre for Emotional Health, Macquarie University

⁶ This is to confirm Joyce Man is the first author and has completed all field work, primary coding and data analysis and the first full draft of this paper.

Abstract

Background and aim: Limited research exists which examine carer experiences with psychological services and other mental health services for individuals with dual disabilities in Australia. This paper aims to explore carer experiences with these services and seek suggestions on ways in which current services could be improved.

Method: Nine parents with an adult offspring with an intellectual disability took part in semi-structured individual interviews where carers discussed their experiences with services that were accessed in the past two years for their adult offspring with intellectual disability and co-morbid mental health or challenging behaviour.

Results: More negative than positive experiences were reported by carers with mental health services that were viewed to hold limited expertise in dual disabilities. Carers reported the importance of collaboration, applying special considerations and adjustments to suit the needs of their child with an intellectual disability. Difficulties in accessing appropriate services were also highlighted.

Conclusions: Findings from this paper have implications for service provision, training and person centred practices for practitioners working with clients and their families with an intellectual disability.

Introduction

Literature on carer coping highlights the significant stress and burden associated with caring for an individual with an intellectual disability (e.g. Rowbotham, Carroll & Cuskelly, 2011). This includes the additional stress relating to the management of maladaptive behaviour associated with an intellectual disability (Hill & Rose, 2009; Minnes & Woodford, 2005). However, not all families who experience mental health concerns or problematic behavior in their child with an intellectual disability seek help. For families who seek help from mainstream health services, negative experiences are often reported (e.g. McGill, Papachristoforou, & Cooper, 2006). In Australia, a study which assessed parents experiences with health services for persons with an intellectual disability found a number of frustrations including poor relationships with staff, a perceived lack of staff expertise in relation to their son's/daughter's needs, inexperienced staff and frequent staff turnover (Llewellyn, Gething, Kendig, and Cant, 2004). Similarly, researchers in Canada found that parents of youth and adults with a mild intellectual disability reported barriers to accessing services and negative experiences with professionals (Nakamura, Higa-McMillan, Okamura, & Shimabukuro, 2011). In relation to children's services, UK researchers (McGill et al., 2006) surveyed families on their experiences with services for their child with an intellectual disability and challenging behavior. Out of the 66 families surveyed, almost half reported receiving no professional input or unhelpful advice (McGill et al., 2006). Another UK study which assessed mothers of children with an intellectual disability on their experiences with services for their child reported carers viewed generic services as inadequate in meeting their child's needs and highlighted barriers in accessing specialist services (Wodehouse & McGill, 2009). A UK study with carers on their experiences with inpatient mental health care reported the admission process to be disempowering and treatment as inflexible for their individual with an intellectual disability

(Donner, Mutter, & Scior, 2010). Taken together, these findings highlight current inadequacies of mainstream services in meeting the mental health needs of individuals with an intellectual disability and their families.

Psychology services play a pivotal role in the provision of mental health and behaviour intervention services for individuals with an intellectual disability and their families. Studies investigating the experience of adults with an intellectual disability access and use of psychological services have documented mixed findings. In a UK study involving 66 families who had accessed services to address challenging behavior, 44% of families reported psychological services as unhelpful, while 27% considered at least one service that was helpful (McGill et al., 2006). Additionally, from participants who had accessed psychological services, 19% were satisfied while 66% were dissatisfied (McGill et al., 2006). However, reasons for helpfulness and satisfaction ratings were not given. Further research into the experience of carers from a variety of psychological services is required to provide a more comprehensive understanding of the experiences with psychological services for individuals with a range of intellectual and verbal levels.

Furthermore, given the majority of these studies were conducted in the UK, findings may not necessary generalise to the Australian context. Psychologists in the UK and Australia differ in their training in intellectual disabilities, with UK psychologists receiving more formal training than their Australian counterparts. For example, doctoral clinical psychology students are required to complete a 6 month placement in intellectual disabilities in the UK (British Psychological Society, 2005). Conversely, specific training in intellectual disability in Australia is rarely provided within postgraduate training with disability placements not being a mandatory requirement. To date, no Australian studies exploring the experiences of carers with an intellectual disability with psychological services are available.

A crucial component of any mental health service is the assessment phase. For individuals with an intellectual disability and co-morbid mental health disorders, a comprehensive assessment is needed in order to identify underlying mental health causes of an individual's presentation (Costello & Bouras, 2006). In doing so, the recognition of a mental health condition is the first step for individuals with an intellectual disability and their carers to seek appropriate support. Current international and Australian best practice guidelines highlight the importance of a multi-disciplinary, inter-service and collaborative approach when working with individuals with an intellectual disability (e.g., Department of Developmental Disability Neuropsychiatry, 2014; National Institute for Health and Clinical Excellence, 2016). Such guidelines also advocate for mainstream services, to apply reasonable adjustments to standard protocols and practices to accommodate to the special needs of this population.

Recently, an Australian survey conducted with psychologists in government disability settings, non-government organisations and private practice settings found psychologists reported modifying mainstream clinical practice to suit the needs of individuals with an intellectual disability and mental health concerns, and collaborating with carers and other professionals to be commonplace practices (Man, Kangas, Sweller & Trollor, 2016) [*As outlined in Chapter 3*]. In fact, of the psychologists who reported conducting mental health assessments, 96% reported interviewing family/carers while 89% reported interviewing the client with an intellectual disability (Man et al., 2016). This suggests the important role of carers as informants in the assessment process. However, a number of practical barriers to best practice implementation were noted by psychologists. Barriers included under resourced services impacting on access to specialised assessment tools and access to mainstream mental health services for adults with an intellectual disability. Organisational issues such as collaboration difficulties between disability and mental health services were also noted. In a separate

Australian study, based on a focus group design involving psychologists working with clients with an intellectual disability, similar views regarding best practice that were consistent with international best practice guidelines were reported (Man & Kangas, 2016) [*Chapter 4*].

Collectively, these findings suggest that psychologists in disabilities report practices that are consistent with best practice recommendations yet they experience barriers to putting them into practice. Currently, limited research exists examining the specific assessment practices of psychologists when working with individuals with dual disabilities. Given that psychologists report that carers play an instrumental role during mental health assessment, whether this is reflected in practice in the experience of carers will require further investigation.

On the basis that existing research findings often report negative experiences of carers regarding their contact with mental health services, it would be important to examine suggestions on how carer experiences could be improved. A UK study investigated views of residential mental health services via focus groups with service users and staff from a variety of roles (Kroese, Rose, Heer and O'Brien, 2013). Service users as well as staff also noted the importance of regular reviews, and training in dual disabilities. Another UK study (Ali et al., 2013) involved interviews with carers of individuals with mild to moderate intellectual disabilities on suggestions for improving the quality of health care. Carers reported the need for reasonable adjustments to accommodate the needs of people with intellectual disability, and a system to highlight to staff the presence of intellectual disability (Ali et al., 2013).

As noted, at present, limited Australian research exists concerning the experiences and suggestions of carers of individuals with an intellectual disability. This is necessary given the differences in service models in Australia compared to the UK. In Australia, mental health services for individuals with dual disabilities are largely serviced by mainstream mental health services with a small number of specialist services available in select states. In the UK

however, individuals with an intellectual disability typically access mainstream mental health services while those with profound or severe intellectual disabilities typically receive specialist intellectual disability health services which encompass community and inpatient services (O'Brien and Rose, 2010). Given these differences, research into carer experiences and suggestions within the Australian context is required to enable specific improvements to be made to Australian services.

Mental health and challenging behaviour services may be provided from a variety of sources including mainstream mental health inpatient and outpatient services, government and non-government disability services, as well as consultations with specialist clinics and private psychiatrists and other health professionals. To date, research in this field has predominantly focused on inpatient mental health facilities with findings generally reporting negative experiences of carers. Current studies on outpatient services experienced by carers are limited to experiences with GPs (Turk, Kerry, Corney, Rowlands & Khattran, 2010).

Furthermore, given the pivotal role of carers as informants, no studies exist on carer experiences with the assessment process within mental health services for individuals with an intellectual disability. As there are differences in service models and service provision of mental health and disability services in Australia, suggestions on how services can be improved from the perspectives of service recipients within the Australian context is also needed. In particular, the experience of carers accessing other types of disability and mental health services will be worthy of further investigation given the systemic nature of disability support. This will not only provide a comparison with experiences between settings but also provide a broader picture of experiences for individuals with an intellectual disability and their families.

Currently, the Australian National Disability Insurance Scheme (NDIS) is creating significant changes in the way disability and mental health services operate (National Disability Insurance

Scheme, 2014). No study to date has specifically offered opportunities to carers on ways in which current services can better meet their needs and their perspective on whether such services are in line with their view of best practice. Suggestions on ways services could be improved should be an important consideration in shaping future services to better meet the needs of this specialist population.

Given the gaps outlined in this field, there were two aims to this study : 1) to explore carers (parent/guardians) experiences with mainstream mental health care including psychological services and mental health assessments for their offspring with an intellectual disability; and 2) to evaluate carer suggestions on ways to improve existing mainstream mental health services within the Australian context.

Method

Procedure

This paper is based on the follow-up phase of a larger study involving online surveys with family carers with a child/adult offspring with an intellectual disability (as outlined in Chapter 6). Inclusion criteria consisted of parents of children of any age with an intellectual disability who had received a mental health service within the past two years in Australia. Only parents with adequate spoken English were eligible. Following institutional ethics approval, participants were recruited via a variety of formats which included: advertising via the first author's networks, professional psychology in disability networks, local papers, via email to non-government organisations, carer groups and the interest group of the Australian Psychological Society via online group forums of national disability non-government organisations, advocacy groups and carer groups. Ethics approval was also sought from a local

health district which enabled distribution of the study flyer to local public health services, which included a number of specialist disability health services and developmental assessment centres.

Following completion of the online survey (Chapter 6), participants who indicated interest in participating in phase two of the study were contacted and either face to face or telephone interviews (for participants located outside of New South Wales) were arranged. Interviews were audio taped to assist with transcriptions for qualitative analyses. Each interview took approximately 50-90 minutes. Carers were asked four open ended questions relating to 1) the nature of their contact with services, 2) their experiences with any psychological services, 3) the assessment process of the service, and 4) suggestions on ways to improve services in general for individuals with an intellectual disability. See appendix F, p. 260 for interview questions.

Participant characteristics

Nine parents (seven females, two males) with an adult offspring with an intellectual disability took part in individual face to face or phone interviews. This study was unable to recruit an adequate number of individuals with intellectual disabilities to allow for saturation of themes for service users. As a result, findings from a single service user were removed from thematic analysis. Of the nine participants, six resided and received services in New South Wales while the remaining three carers received services from Australian Capital Territory, Queensland and Western Australia. Carers were aged between 45 and 75 years ($M = 54.25$, $SD = 10$), although one carer did not report their age. Seven carers had a son with an intellectual disability, and two carers had daughters. Offspring of carers with an intellectual disability were aged between 18 and 39 years ($M = 25.78$, $SD = 6.14$). Six carers (67%) reported their offspring had a mental health condition, four (44%) reported a diagnosis of autism, while two (22%)

reported a congenital syndrome. Six carers (67%) reported accessing at least three services for their offspring with an intellectual disability to manage challenging behaviours or mental health concerns. Eight carers (89%) also reported accessing a combination of disability and mental health services. Psychiatrists and psychologists were the most sought after professionals for their adult offspring with an intellectual disability while assessment and intervention services were the most commonly received services. See Table 1 for a list of professionals and services sought by carers.

Table 1

Types of Professionals and Nature of Services sought by carers

	Number of carers receiving service	Percentage of total sample ($N = 9$)
Type of professional sought		
Psychiatrist	7	77.8
Psychologist	6	66.7
Other	7	77.8
Clinical/specialist psychologist	4	44.4
Behaviour support practitioner	4	44.4
Nurse	4	44.4
Psychiatric registrar	2	22.2
Nature of service sought		
Assessment	8	88.9
Intervention	7	77.8
Parent training and support	6	66.7
Consultation/clinic	6	66.7
Medical review	6	66.7
Crisis mental health	5	55.6
Other	2	22.2

Note. Other professionals sought include: Geriatrician, case manager, supported employment staff, general practitioner, welfare officer, emergency care staff and police. Other service natures include: Supported employment, health reviews

Data analysis

To examine the two aims of the study, thematic analysis (Braun & Clarke, 2006) was used to analyse transcripts from each interview to identify themes arising from the four aims of the study. N Vivo software (version 11) was used by the first author to manage the coding process during all phases of the thematic analysis. Derived themes and sub-themes were also reviewed by the co-author. Following this, revisions were made to condense and simplify the structure of the themes and sub-themes. Where discrepancies in coding emerged between raters, discussions ensued until 100% agreement was reached.

Results

During discussion on experiences with mental health services, carers referred to their experiences with a variety of health and disability services. Hence, themes discussed below relate to a variety of health and disability services accessed by participants and are not exclusive to mainstream mental health services. Overall, six themes and 11 sub-themes emerged. The main themes identified were: service access, degree of collaboration, impact of service, operational and resource limitations, accommodating to individual needs and limited service expertise. See Table 2 for a full list of themes and sub-themes.

Table 2

Emerging Themes and Subthemes

Themes	Subthemes
Service access	Navigating maze of services Limited service availability Difficulty coping
Degree of collaboration	
Impact of service	Positive impact of service Limited or unhelpful service Anticipated impact of NDIS
Operational and resource limitations	Operational limitations and suggestions Resource limitations and suggestions
Accommodating to individual needs	
Limited service expertise	Assessment limitations Limited expertise in ID Specialist service limitations

Theme 1: Service access

Three sub-themes emerged in relation to difficulties encountered in locating appropriate services.

Navigating maze of services.

Carers reported barriers in accessing and locating appropriate services for their offspring with dual disabilities. Carers described an arduous process with little information available to guide them on where to go for appropriate mental health services.

I don't think there's a rock that I haven't unturned, which is frustrating. I think at one time my husband was on the phone out there and Reece is going, "Ring someone, ring someone." And we're going, "We're trying. We're trying." Because he was asking for help too but we didn't know. We were trying everything and anything. (Kim⁷)

Carers also described their adult offspring being rejected from mainstream mental health services and falling between service gaps.

She has access to that now, but we had major problems getting access to that service because the system was just so stuffed basically and they were overloaded. They weren't taking people from outside the area. And we'd only get through by pulling strings. (Michael)

They're doing an assessment, but they said, "We don't have space. We don't take people with an intellectual disability." This is what they said. "We don't take people with intellectual disability in the hospital with autism." Then I go – and I'll always remember this because I've talked about this in written papers – "But where are we meant to go? I'm on my own. There's no one at home with me. I can't look after my son. He's bloody this big. What are you talking about? You don't take people like this?" (Alison)

It's just a whole system and then, like I said, with the police saying that they won't help because of The Mental Health Act. Then you go to the hospital and they won't help because it's a disability and ... I mean, that's just ridiculous. It's just like (*sic*) too-hard basket. "We're not going to deal with it." (Kim)

⁷ All carer names have been changed to preserve confidentiality

Limited service availability.

Carers reported minimal support from services for referrals to more appropriate services and having to find this information out on their own.

And it's not until after you start mentioning her name in places, "Oh yes, we've heard of her." And I'm thinking, well why didn't anyone say anything sooner when I start saying I've got these issues with Kyle. People just don't think to say anything. (Mary)

So we've had to source it out. Apart from the fact that yes, we've used the government agencies and we just put words out and we've contacted other networks of other carers, just asking them for who they recommend. We've had names come up for that sort of stuff. So we tend to use our own network of carer's support network to get information on what's worked and what hasn't worked. (Michael)

Carers also highlighted mental health services were often scarce and the barriers associated with being accepted by these services.

I did all the papers for the group home. The group home never happened. They kept saying there's no space, there's no beds, they won't take him, he can't go. The hospital wanted him to go, but there was no way to get into the group home. (Alison)

There were also huge costs associated with private services when public services were unavailable or unsuitable.

They really need general anaesthetic, do the x rays, fill in cavities, clean the teeth and come back again in a few years. That's what they really need. That's not covered by the NDIS or anything. If we can't afford \$4000 every couple of years his teeth just rot. (Val)

One carer also highlighted the difference between children and adult mental health services.

The access and quality is compromised, has been compromised for years, it's been that way for a number of years. While she was under 18 the services were fine. Once they hit 18 they go into a larger pool which services are not at all well-resourced enough to cope with the demand. Once she became an adult it's been very, very hard. (Michael)

Difficulty coping.

Contact with mental health services was typically in response to a crisis with the individual with an intellectual disability. Carers noted a sense of desperation with some families relinquishing care when no other options were available.

By then, my health was gone. I was having trouble walking because of the hip issue. It was disintegrating. That was another thing. I couldn't run away fast anymore. So, I moved up here and I wrote a letter saying, "You haven't arranged accommodation. You've had 18 months to do so. I'm too much at risk. I will not be picking him up." That was that. Otherwise – I say to everybody, and I mean it – you're coming to my funeral. I wouldn't be here. (June)

What ended up happening, then, the next step for us, was we were told, "Look, unfortunately, to get another level is that you have to sign him as homeless. That's the only way." So again more trauma because to us he has a home but he can't live here. We love him to death. Those words are just trauma for us but then I went into worker's mode the next day after I was a mess to think, you know what, it's just a word. (Kim)

Several carers found managing their adult offspring's presentation particularly difficult as single parents with limited supports to draw on during these moments of crisis. Regarding her

experience with an inpatient mental health ward, one mother commented “No one ever said, ‘Would you like someone to talk to?’ Never, never in 10 years did anyone offer that to me, a social worker, even if I was crying my eyes out” (Kim).

But, really, at the end of the day, I felt quite alone. I’d be driving along with him after tenpin bowling, particularly, and he’d be let down by some girl, and I’d be literally driving as fast as I could so I could get home, and feeling really vulnerable because he’s right there and angry. (June)

Theme 2: Degree of collaboration

In discussing the experiences with services, the working relationship between the carer and service provider was an important and memorable aspect of this encounter. Carers described effective collaborative relationships with a range of service providers and clinicians where their viewpoints and knowledge about the individual with intellectual disability were taken into account in decision making.

For example, one carer described her experience with a specialist psychiatrist as follows:

So they’re on the same page as me. So, yes, it’s nice to know I’m being supported as much as Kyle is. And they know that I’m not just somebody who wants to just put him on medication, like I’m happy to work with them. (Mary)

This same carer also described a positive working relationship with a disability service psychologist:

So he was really good in the way that he informed me and gave me pointers on how to deal with Kyle and what he had discussed with Kyle (Mary).

Carers also highlighted the crucial nature of their role in ensuring services meet the needs of their offspring with an intellectual disability.

Yeah, I'm very organised now when it comes to paperwork and (individual with intellectual disability). If I'm going to a new provider now I've got it ready to go, a pack of everything (Sue).

However, not all experiences with service providers were evaluated as being collaborative by carers. That is, carers also described poor working relationships with service providers and clinicians where they were not consulted regarding decision making in relation to their son/daughter with an intellectual disability. For example, one carer described her lack of collaborative experience with a mainstream inpatient mental health facility as follows:

They sectioned him at that point and took him up there, and I think he did stay in there. Nothing came back to me. I did make them liaise with (private psychiatrist) but there was no feedback, no communication. (June)

Given the perceived lack of collaboration by some service providers, some carers described needing to constantly advocate for their (carer) needs as well as their adult offspring's needs and rights. Some carers further sought action with formal complaints to the service with some making contact with ministers.

I had to go to our local member, (*sic*) had to come down and issue a ministerial directive, kick in the butt to the Department down in (local geographical area) and then make the change last minute Friday afternoon. We had to go to the top, come down with an atom bomb on top of the department for the minister. (Michael)

I've been told by the Health Minister that there was not much they could do and that I should be trying other things. And I ended up having a stroke because of the stress.

After spending five days on life support and a month in hospital, I came out and revisited my local Member, and with a push they helped with social workers through the hospital to get me a case manager. (Mary)

Some carers further described instrumental efforts in creating change in mental health service provision for individuals with an intellectual disability.

One (initiative) is the neuropsychiatry developmental disability health network. I have been part of that implementation process in the last few months and what will come out of that will be models of care, particular models of care established. This particular capability framework will be used to assist in establishment of these models of care.

(Andrew)

At times, carers and service providers/clinicians disagreed about recommendations or held inaccurate views on the roles of mental health professionals. This seemed to cause conflict leading to carers feeling unheard and their expectations of the professional unmet. For example, several mothers commented:

Because I was asking for the unconventional, for him to be chemically castrated, there was a lot of, from, especially even from the psychiatrist, how dare I" (Mary).

So you need people who specialise in that area, you can't have someone who's a psychiatrist looking after high performing businessmen who had nervous breakdowns looking after somebody who is anxious because the bus driver doesn't take them the

route to go to work, to go to their day program or they're getting staff that they don't know every day. (Val)

Some carers noted their needs and regard for their safety and wellbeing were often ignored. "My frustration, really, was two things. One, they just dismissed him and gave no regard to any form of ongoing care, and, two, they had no regard for my safety" (June).

Theme 3: Impact of service

The third theme reflected experiences of services in relation to the perceived helpfulness. Three sub-themes were generated in relation to positive and unhelpful experiences and views on the anticipated impact of the National Disability Insurance Scheme (NDIS) on service provision and delivery.

Positive impact of service.

Carers expressed pride in making progress and overcoming their initial difficulties. Improvements in daily functioning and wellbeing were noted. Several mothers commented:

He's absolutely so much better now. He is, in fact, so much better that (private psychiatrist) wants to take him off all of his medication (June).

One of the things that helped Shane recover was art, and Shane is now an artist. (Alison)

Carers also readily recalled the times when a service was responsive to their needs, showed expertise in intellectual disabilities, and maintained rapport and consulted with carers during the service.

There were a very good couple of psychiatrists up there in the unit. They had seen James in the home. They'd come down to see him in the home, and they'd sat down and they'd

chatted with him. I had these people on speed dial in my phone. I rang them and I said – I had a query about the amount of PRN I could give him. They could hear him in the background. I finished the conversation, but I went outside because I was too scared to go in. I was just standing there, and the next thing they pulled up in a car. It was only like 10 minutes later. (June)

On her experiences with a disability psychologist, several mothers commented:

He worked well in that sense in being able to work with two and discuss in different depths, so he could be on Kyle's level one minute but be on my level the next (Mary).

I think the psychologist was very caring and was someone for Shane to talk to. He often told me how Shane was going. He told me any concerns he had, and I think he gave me some good advice. To take Shane out of hospital, I think that was very good advice.

(Alison)

In relation to her experiences with a private psychiatrist, one mother noted:

I think she has seen a lot of people with intellectual disability. She'll spend a lot of time in the meeting just sitting with him and drawing pictures with him, she'll just gauge how he is. (Val)

Limited or unhelpful service.

At times, the recommendations provided by a clinician/professional were deemed impractical.

They were one organisation that I called about the crisis and they said they'll send some crisis behaviour management in, who was a psychologist. Her crisis management was a

piece of paper and some mindfulness and to get him to push his feet into the ground and gave me like a bottle of water with glitter in it and said give that to him twice a day and get him to shake it and say “When you’re angry, look at the glitter and calm down. My husband wanted to throw that because it was like that is our crisis behaviour support management? That’s it? Again, we’re like let down, thinking is that it, that’s all you’re going to do for him and help us manage this? (Kim)

It (Behaviour Invention and Support Plan) was repetitive, the order was confusing. It didn’t introduce Andy in a helpful order, there were ideas that were repeated in the plan. He was referred as she in some places, I think this was from someone else’s BIS Plan. I had to read it to make sure it was all correct. (Val)

Some carers described the environment in which the disability group home setting was deemed to be unsafe for their child and expressed worry for their safety.

Yeah, and that's very hard, particularly in someone like, with (co-resident with intellectual disability) who's in the house with (individual with intellectual disability) where she's been sexually abused, she's had to move 17 times, there's a lot of issues, and that sort of stuff. And even (individual with intellectual disability) been interfered with when she was a child at one of the (government disability service) respite services, which had to be dealt with at that time. So there's been issues all the way through. (Michael)

The inpatient hospital setting was also deemed unsafe at times by carers.

The nursing staff used to just hide in the office. The office has got glass all the way around it, and it’s got doors, it’s protected, and there was no one on the floor. So, all the

patients are just wandering around, and the only people that are on the floor are security guards. There's no clinical staff on the floor. (Alison)

A small number of carers also described the detrimental impact of over-medication as a treatment for mental health concerns and/or challenging behaviour.

I'd take him out for lunch, I'd take him as he got a little bit more well (*sic*), but he was very heavily medicated. I remember taking him swimming at Coogee, and he didn't know how to swim anymore. That was scary. He didn't know how to swim. He was on so many meds. That was a turning point. The meds were so high. Even when he left hospital after six months, he was on three things still. He was very zombie like. Very, very zombie like. (Alison)

Anticipated impact of NDIS.

In light of current and upcoming restructuring of disability service provision in Australia, carers expressed both optimism and scepticism around these changes.

And the thing is with the way it's set up, we'll have more control over where the money goes to, we'll spend it. Whether we choose the NDIS to manage it or with ourselves or whatever, there are options coming up. So it appears we'll have more control. (Michael)

I think there will be conflict for a very long time. The organisations will struggle to embrace a person centred model not a product delivery, take it or leave it model. I think a lot of the not for profits will struggle. (Val)

Many carers also expressed mixed feelings and uncertainty regarding what the changes will look like in practice.

I think that's going to cause a lot of problems for a lot of people, older clients. A lot of them are refusing it. They don't want it. I'm sort of open minded. I'll wait and see how it all pans out, really. It's going to have a few teething problems. (Sue)

Theme 4: Operational and resource limitations

This theme related to carers' negative experiences with services in relation to service delivery and provision. Two sub-themes were generated: Operational limitations and suggestions and Resource limitations and suggestions.

Operational limitations and suggestions.

Problems related to how both mental health and disability services were conducted were highlighted by a majority of carers. In particular, carers identified a lack of coordination between services and clinicians.

I've always found the hospital system like that. It's not a team, family environment and no one got any information. When he was always admitted as a child, oh, my God, he was there every week and they'd still ask me all the questions that they'd asked every time. (Kim)

In addition, numerous examples of a lack of accountability of services were offered. Carers reported ineffective feedback processes, particularly with group home settings in response to complaints to the service provider. For instance "*the support workers aren't ... some of the things they are doing highlight red flags and you try and action a complaint and it will get swept under the carpet*" (Sue). Similar experiences with disability group home settings have also been found by carers.

I sat down with the person in charge of this organisation, this service provider's organisation, director for disability, and he had a quick look through the draft ..., 'That's not too bad but we're going to do our own thing. We're going to do our own training.' That's the sort of attitude that this particular organisation has. (Andrew)

But if you complain to the service provider directly, this is my experience, they'll ignore you for a few weeks then they might send you a reply that'll say 'we've checked out your allegations and we believe there's no truth in them. And you write back and say 'No there is. He's my son and he has wounds all over him or whatever it might be.' If you raise it with (government disability service), they'll say 'we've checked with the service provider and everything's fine. And you'll say it's not. It's just not. Then if you complain to the minister, they'll go back through that process too. (Val)

Carers also noted a lack of follow up care as well as a failure or significant delays in services delivering what was promised. On her experience with an inpatient mental health ward, one mother commented *"there wasn't a follow-up. They sectioned him, the police came, but that was that. Back to my care again"* (June). In relation to her experiences with psychological services from a private consultative service, another mother described:

So I was really very unhappy with (private disability service), a lot of people were unhappy with them. The (parent group) prepaid them for BIS Plans last year and they hadn't done a thing and they sat on the money-\$3000 a pop. (Val)

Systemic concerns were also reported including the impact of high staff turnover.

There's been huge change in staff and it's certainly not the same staff and there's certainly not the same staff now as there was in late 2010. I saw a pretty hopeless

situation with the training of service providers and including the mental health area.

(Andrew)

Some carers offered suggestions on ways systems can be improved to better support parents and to improve service operations.

Then I think maybe support groups for parents because I'm not the only one who has a child, an adult child, with dual diagnosis. There doesn't seem to be a lot of support for dual diagnosis, especially in our situation. (Tracy)

I think all the medical records should be online. They should all be in one place. We should all have e-health. If you present to a hospital, a doctor should be able to open up a file and find the notes. That's what I really think. I think that would be really helpful rather than a thousand times you tell the story over and over. If someone comes in and they've been 20 times in that hospital, you just go bang, bang, "Okay, so he was last here six months ago. He was experiencing this. He's on this medication. He's treated by this doctor." They can just see it all in a file. (Alison)

Maybe even that (*sic*) triage, having a question sheet, "Does your person have an intellectual disability?" They might ask if you're Aboriginal and they might ask all these questions but what about "Does this person have an intellectual disability? Have they been in the hospital system before? What are their needs?" Some real practical what's going on, not just the standard age, Aboriginal this and that. (Kim)

Resource limitations and suggestions

Some carers reported mainstream mental health services were under resourced and which had a detrimental impact on the quality of services.

When you get in there they do know what they're talking about. The problem is they're under-resourced and overwhelmed with the demand, and they're struggling to maintain the day to day operation, and getting appointments, following up appointments and getting the paperwork out. (Michael)

Specifically in relation to hospital settings, carers suggested the need for more recreational activities and flexible spaces for individuals with an intellectual disability who had been admitted as inpatients in mental health wards.

I think for everybody there needs to be quiet rooms. Often the television is going all the time and people are watching the TV, but there needs to be other quieter areas. I think there needs to be meditation. (Alison)

Carers also noted better specialist service availability is required in rural areas.

I'm worried there'll be nothing for people in regional areas where it's not economically viable for a service provider to provide a service there (Val).

A number of suggestions were offered in relation to service resources. Many suggested the need for training in dual disabilities across service sectors which include mental health services, disability services, schools as well as training and support to parents. One mother suggested "they probably need to have training when they're studying. They need to have work training, work placement when they're studying where they get used to people with intellectual disability or autism" (Alison). A majority of carers noted having to seek out information themselves, relying on support networks for information and accumulating knowledge through caring experiences.

It's easier now to communicate when you know how to communicate with these service providers because if you have no knowledge of anything then you really struggle because you don't know what is going on and what needs pursuing. It's like a blank canvas.

(Michael)

Theme 5: Accommodating to individual needs

Carers described the importance of service flexibility and willingness to accommodate to their son/daughter and their needs as carers. Both positive and negative experiences in relation to this theme were reported. Carers described many examples of ways in which mental health service providers utilised person centred approaches and made reasonable adjustments to their practice to suit the needs of the individual with an intellectual disability and their families.

He used to be admitted, so he used to go in and he'd stay for 48 hours and then come home. I would just ring children's ward and say, "We're coming." And they'd be at the door and they'd be ready for us. (Kim)

He's happy to go into his psychiatrists' office because it's just an office and it's fun. She always draws pictures for him, it's social so he doesn't mind it there. So he doesn't really view that as a medical appointment. Anywhere else he'll get the (fight or) flight reflex and he'll run away. (Val)

He had the special nurse because they wanted to protect him from the other people. It was never about Shane going off and hitting other people. I noticed on the ward they'd often have – before he had the special nurse for him – the security guards would always be pretty close. (Alison)

Some carers offered suggestions on ways to improve person centred practices in mainstream mental health settings.

They need more than one appointment, for a start. They need to do at least two or three to get a proper view of the family, how Sara works and thinks and how she's understanding what's going on around her. (Sue)

You can have different models of care out there in support. You can have teams. You can have a model of care for people who have greater need because of their mental condition and you can formulate to have a team system, a team, or you can just rely upon, as my son is doing, and just having a psychiatrist and a mental health nurse. Yeah, so there's different means by which you can tackle this problem. (Andrew)

On the other hand, an equal number of examples were given regarding ways in which mainstream mental health and disability services were not flexible to the needs of the individual with an intellectual disability and their families.

One carer described "they don't get you can't just make a person with intellectual disability wait because you're running late or you've put somebody before them or whatever (Val).

Another mother expressed "Now my problem is with Kyle's inappropriate sexual behaviours, will the camps take him because they're obviously male and female; getting the right support systems now. So it's great to sort of have these things but then they're not always tailored to your personal needs."

In her description of her experiences with her son's group home, one carer expressed:

So they don't know the guys. Then the guys get upset. Because they're wanting to say. 'You've got it all wrong'. They're dressed in each other's clothing, they don't know

which one's which. It's not like they're in hospital with identification bracelets where they're like 'Right you're Andy, you're meant to have this medication. (Val)

Theme 6: Limited Service Expertise

Carers described experiencing limited expertise in dual disabilities from a variety of services and professionals. These are described via three sub-themes described below.

Assessment limitations.

For carers who accessed mental health services, many instances of uncertainty regarding the diagnosis of the individual with intellectual disability were given.

“ I don't think they expect there to be a clear answer either, because Kyle just doesn't want to discuss things either” (Mary).

The psychiatrist was tossing around – because autistic is his diagnosis – the psychiatrist was toying with the label schizophrenia without actually wanting to come out and say it, which I believe that he was, and it was out of control because he was behaving really quite strangely and had been for a while. (June)

There were also examples of diagnostic disagreements between clinicians. One carer explained ‘the neurologist diagnosed him with dementia but the geriatrician doesn't agree with that diagnosis, the specialist geriatrician who looks after people with dementia’ (Tracy).

In the beginning, when he was about 12, he was diagnosed with schizophrenia, depression and anxiety and we were under another psychiatrist privately until he was transferred to the dual disability team, which is the government one. That psychiatrist said no it's not

mental illness, it's actually autism. They really don't know. No one can give us a straight answer. (Tracy)

Some examples of a lack of comprehensive mental health assessment were also reported.

I don't even think they did any. I mean, they did just the walk around the ward and "what's he doing today" but they weren't doing anything, so what would they be checking?" (Kim).

Limited expertise in intellectual disability.

Carers perceived a range of services including mental health, disability and accommodation services to lack expertise in intellectual disabilities and mental health concerns.

So they do serve their purpose and they do have, I suppose, at the crisis point but because they don't actually go into actual disabilities, it's finding somebody who can deal with an intellectual disability and mental health issues at the same time, not just the mental health issues. I think not a lot go into that, especially if they're in private health. (Mary)

Some services were described to lack awareness of current national policies that govern their work in disabilities and limited experience working with individuals with an intellectual disability.

I think with mental illness and now where he's at with this stage, adults, I think I've now just in the last six months experienced where he just really doesn't fit or the system doesn't really support not only people with a disability or understand that their mental illness may present differently to the standard norm of textbook mental illness. (Kim)

He has a moderate intellectual disability. I go in there, his undies are back to front because they've just said, "Go and shower yourself or dress yourself." He can't do any of that. He had body odour problems because he wasn't washed. No one asked. I just can't believe no one asked for someone who hasn't got those skills. They didn't even find out, you know, can he wash himself, can he dress himself, all those things. (Kim)

Speciality services scarce.

Many carers described the limited availability and access to specialist services in dual disabilities. In relation to her experience with specialist services, one mother commented "the doctor only comes down, I think it's every three weeks. There's a psychiatric nurse attached to that service. They actually discharged us because they didn't know what to do with him" (Tracy). Another carer noted a scarcity of psychologists specialising in dual disabilities. "Psychologists in the state mental health service in this state, very few are qualified to be able to deal with a person with disability with development issues, very, very few" (Andrew).

Finally, improving the availability of specialist services was often suggested by carers.

I really believe there needs to be dedicated intellectual disability clinics, with the dental, physical, for everything but particularly the mental illness too, they can't tell you what's upsetting them, all they do is act out, you know, punch holes in walls or pull their own toenails out, pull their hair out or head butt walls. (Val)

We need special facilities and special wards for people with an intellectual disability, and that's what I've been lobbying for, talking about, for the last seven years. We can't put people with intellectual disability in these general wards with these other people. We need special units, special wards, we need specially trained staff. (Alison)

Discussion

The overall aim of this study was to explore the experiences of carers with mainstream mental health services received by individuals with dual disabilities and their families. As a result of the open ended interviews conducted, carers discussed their experiences with a range of services accessed by their offspring with an intellectual disability. This included mainstream mental health, health and disability services. All carers who took part in this project had an adult aged offspring aged 18 years or older with an intellectual disability. Overall, carers described many examples of helpful and positive experiences with services, yet despite this, mainstream services were typically described as lacking in expertise in dual disabilities with existing service systems often failing to meet carer needs and the mental health needs of their adult offspring with an intellectual disability. Themes generated were with reference to service access, collaboration, impact of service, operational and resource limitations, accommodation to individual needs and service expertise.

In relation to working relationships with service providers, the majority of carers experienced instances of collaboration as well as difficulties in establishing collaborative relations with the service providers. Effective collaborative relationships at times were only achieved following carer attempts to specifically advocate for the needs of their offspring with an intellectual disability. Carers described valuing instances when their points of view were taken into consideration during decision making for their offspring and expressed dissatisfaction when they were not consulted by service providers.

In the current research, instances of collaboration were outweighed by instances where carers felt their roles as experts in their adult offspring with an intellectual disability were ignored. However, all carers described experiences in which they were not consulted with

during clinical decision making. This contradicts with findings from a large scale UK study in a hospital setting by Tuffrey-Wijne and colleagues (2013) where a majority of hospital staff reported viewing involving carers as standard practice. Although many respected the role of carers as workers, this often did not extend to the view of carers as experts and collaborative partners. Staff viewed carer's role in the hospital setting to consist of: providing a sense of familiarity for the individual with intellectual disability, acting as an interpreter of patient communication, preventing ward disturbance, serving as a key informant and supporting with basic nursing care (Tuffrey-Wijne et al., 2013).

Another qualitative study involving carers on their experience with mainstream mental health services found similar findings regarding carers not feeling heard and minimal flexibility in service provision (Donner, Mutter & Scior, 2010). This contrasts with the recommendations of international practice guidelines, where collaboration and valuing the role of carers in servicing individuals with an intellectual disability is considered an essential part of best practice (Department of Developmental Disability Neuropsychiatry, 2014; National Institute for Health and Care Excellence, 2016). At times however, dissatisfaction with services can be attributed to unrealistic preconceived ideas from carers regarding the role of mental health professionals and service providers and the services they provide. For instance, at times, carers sought professionals with specific views on how the individual with an intellectual disability should be best helped and experienced dissatisfaction when professionals' recommendations differed from their views. Disagreements also arose between carers and professionals when there were conflicts between protecting the rights of the individual with intellectual disability and respecting the carer's views on what was best for their child.

All carers understood the necessity of service providers to apply special considerations and reasonable adjustments to mainstream practice in order to meet the needs of their adult

offspring with an intellectual disability. Carers appreciated services applying flexibility to their service delivery and utilisation of resources to make their offspring feel at ease and receptive to the service. When services were unwilling to apply reasonable adjustments to their practices, this was seen as detrimental to the working relationship between carer and service provider with negative impacts on the individual with intellectual disability receiving the service. Again, reasonable adjustments are considered standard practice when working with individuals with an intellectual disability as outlined in international practice guidelines (Department of Developmental Disability Neuropsychiatry, 2014; National Institute for Health and Care Excellence, 2016). Given these findings, mainstream services need to make attempts to accommodate to the specialist needs of this population. The reasonable adjustments described by carers in this study were relatively simple adjustments such as using games and pictures to build rapport with the individual, keeping language simple, minimising appointment wait times and using visual supports.

Carers also noted many operational and resource issues impacting on service availability, access and quality. Carers frequently reported a shortage of specialist services in dual disabilities yet often expressed dissatisfaction with these services when they were received. Common criticisms related to accessibility and quality of such services as a result of service scarcity. Many carers of individuals with dual disabilities experienced barriers in locating and accessing a service able to meet the mental health needs of individuals with an intellectual disability, particularly during times of crisis. Some carers also described being turned away from mainstream mental health services. Similar carer experiences have been reported in other qualitative studies (e.g., Donner et al., 2010; Wodehouse & McGill, 2009) where many difficulties in accessing mainstream mental health service have been found. A data linkage study in New South Wales also found an under-representation of people with an intellectual

disability in ambulatory mental health settings that may be reflective of difficulties associated with service access (Howlett, Florio, Xu, & Trollor, 2014). This issue has previously been reported by Bennett (2014) and Mohr, Curran, Coutts and Deniis, (2002) where the dichotomising of mental health and disability services has resulted in a lack of expertise in dual disabilities. As a result, this often left individuals with dual disabilities falling between service gaps. Furthermore, carers in this study frequently mentioned a lack of expertise in intellectual disabilities in mainstream mental health services. Suggestions for training across a variety of mental health and disability services in dual disabilities were made in view of increasing competency in this area.

With the changing landscape of disability service provision in Australia, carers contemplated on the anticipated impact of the NDIS. Carers displayed skepticism regarding the impact of the NDIS on service provision for their son or daughter with an intellectual disability. Although in principle, the NDIS allows for more flexibility, choice and control for individuals with an intellectual disability and their families, the fact remains that current service structures experience major barriers in meeting the complex mental health needs of many individuals with an intellectual disability and their families. As the NDIS continues to be rolled out across Australia, on the basis of the current findings, more clarity around mental health service provision for individuals with intellectual disability is needed. The NDIS was also developed on the basis on person centred principles and suggestions have been made to ensure such principles are at the forefront of person centred planning particularly for individuals with complex support needs (Collings, Dew, & Dowse, 2016). To this end, it is promising to note recent federal and state government initiatives to improve accessibility to health services for individuals with disabilities via the Disability Inclusion Action Plan 2016-2019 (NSW Government Health, 2016) for health services in New South Wales and inclusion of special

mention of individuals with an intellectual disability within the Primary Health Network, Primary Mental Health Care Flexible Funding Pool Implementation Guidance (Department of Health, 2016).

During the interview process, carers typically described how they first came in contact with mental health services. Uncertainty regarding their offspring's diagnosis coupled with a lack of information on where to go to for help resulted in carers feeling disempowered and vulnerable. These findings parallel those of a large scale study with Australian carers supporting a family member with a disability at home which examined service and support needs. Carers in this study expressed the need for information on services available to them and in relation to future support needs for their family members with a disability (Burton-Smith, McVilly, Yazbeck, Parmenter & Tsutsui, 2009). Furthermore, the current study also found that contact with mental health services for individuals with an intellectual disability were often a result of a mental health crisis and admission to inpatient services were typically not straight forward and required advocacy efforts on the part of carers and other professionals. This is consistent with findings from a focus group study with carers on their experiences with mainstream mental health services where carers described feeling isolated and lacking in social supports during these distressing times while services did little to acknowledge their needs (O'Brien & Rose, 2010). Carers play a crucial role in assisting the individual with an intellectual disability to access appropriate services as well as serving as key informants and advocates for their child. More needs to be done to support carers to ease their burden and reduce barriers to service access. One example of an initiative to improve the hospital process have been made in the UK with the trialling of a hospital passport which identifies the individual's intellectual disability and support needs to ensure an effective and timely service (Blair, 2011).

Notwithstanding, carers also identified many positive experiences with services accessed. Respecting the carer role and working in collaboration during mental health service delivery, awareness of policies and best practices governing service supports with individuals with an intellectual disability, utilisation of person centred practices and accommodating to individual needs were all highly valued by participating carers; components which are aligned with evidence based practices. The utilisation of person centred practices reported of Australian mental health and disability services are also increasingly being adopted internationally such as in the UK, USA, Canada and the Netherlands (Collings et al., 2016; Herps, Buntinx & Curfs, 2016; Holburn, Jacobson, Schwartz, Flory & Vietze, 2004; Mansell & Beadle-Brown, 2004; Rasheed, Fore & Miller, 2006).

Study Strengths and Limitations

This study adds to our understanding of the experiences of carers with mental health and disability services in Australia. One of the study's strengths is the representation of carers from multiple Australian states including Western Australia, Australian Capital Territory and Queensland.

A number of limitations also need to be acknowledged. Firstly, all participating carers were Caucasian, hence findings cannot be generalised to culturally and linguistically diverse families. Furthermore, a majority of participating carers held strong opinions regarding their experiences with services and it is likely findings may have been negatively skewed. In fact, on several occasions, carers offered to provide additional written information in relation to formal complaints regarding service delivery previously made to various governing bodies. Thus, participating carers may have played a vocal role in relation to service provision for their offspring with an intellectual disability. Furthermore, no carers of children with an intellectual

disability took part in this study. Carers with adult aged children with an intellectual disability may possess needs and experiences with services that are likely to differ from carers with young children who may require more support to adjust to their child's delayed development and to seek early intervention services.

It is beyond the scope of this study to explore the experiences of individuals with intellectual disabilities with the mental health and disability services they receive. Further research on experiences with a variety of mental health and disability services accessed by individuals with a range of intellectual and verbal levels is required. Whether service users' experiences with mental health services differ from their carers would be important to uncover in view of improving service quality and accessibility.

Study Implications and Recommendations

Family carers may be considered 'experts in their own right' and have a critical role to play in the health and wellbeing of their son or daughter with an intellectual disability. The negative experiences reported by carers from this study suggest their unique role is not always taken into consideration nor valued by service providers. To combat this, family carers should be included into regular review and consultation with service providers. During mental health assessments, carers typically serve as key informants of the individual with intellectual disability with knowledge of baseline and post baseline functioning and history of the individual. Carers can also provide valuable information regarding what types of reasonable adjustments are required to suit the individual needs of their adult offspring with an intellectual disability. To facilitate the implementation of reasonable adjustments in the hospital setting, Tuffrey-Wijne and colleagues (2013) made a number of recommendations: Identify systems and policies supporting reasonable adjustments to be made, allocation of additional and

resources to enable adjustments, managerial support and support within the organisational structure and improving staff attitudes, and understanding of reasonable adjustments to assist individuals with an intellectual disability. On a larger scale, both individuals with an intellectual disability and family carers should be included in the consultation process during the review of service models, structures and policies concerning individuals with an intellectual disability. Efforts should be made to include carers from a variety of geographical locations, socio-economic and cultural backgrounds to ensure their views are represented.

Carers in this study also offered a variety of suggestions to current disability and mental health services to maximise inclusiveness for individuals with an intellectual disability and to make the experience a more empowering and helpful one for carers. Information on available services, in particular, specialist services with expertise in both intellectual disabilities and mental health disorders and their referral pathways should be made freely and widely available to carers. Such information could be provided to GPs as well as non-clinical service providers such as day programs, group homes, respite centres that are frequently accessed by individuals with an intellectual disability and their families. In addition, at the commencement of new services, it is recommended that service agreements be established between carers and service providers to clarify expectations for both parties and to establish channels for accountability early into the working relationship. When carers have unrealistic expectations of service providers or there is a lack of accountability from service providers, this will more likely give rise to service dissatisfaction.

Limited expertise in dual disabilities in mainstream services and a lack of specialist services in dual disabilities were clear themes which emerged from this study. More resources are required to improve access to specialist mental health services for individuals with dual disabilities in both urban and rural areas of Australia. Currently, availability of specialist

services is dependent on geographical location where some states and rural areas in Australia are deprived of specialist services altogether. More resources should also be invested in training in dual disabilities based on international best practice standards. These should be tailored to suit the needs of families, a range of professions and a variety of services within the mental health, disability and education sector. For instance, training for families could focus on mental health literacy and knowledge of available services for their son or daughter with intellectual disability. Training for GPs could focus on referral pathways to specialist mental health services and collaboration with other mental health professionals following discharge from inpatient hospital settings to ensure adequate follow up care for the individual. Training for psychiatrists in mainstream hospital settings could incorporate evidence based mental health assessment, knowledge of best practices in relation to psychopharmacology use and incorporating reasonable adjustments and working in collaboration with families and other professionals involved in the care of the individual with intellectual disability. In conclusion, a variety of improvements in service delivery models, resources and practices are required to empower families and support current services to ensure the mental health needs of individuals with an intellectual disability are being met effectively, in a timely manner and in line with international best practice principles.

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APPENDIX F

Interview questions

- 1. Under what circumstances were mental health services sought? Who made the referral? What was the reason for seeking this service?**
- 2. What are your experiences around working with psychologists in these services? What was helpful/unhelpful? What did you see as their role?**
- 3. What are your experiences during the assessment phase of the service? Who was involved? How much were you included in the process?**
- 4. What are your experiences of the services received in general? In what ways can mental health services for your child be improved?**

Bridging Chapter following Phase Three

The final paper arising from this research addressed carer experiences with a range of services received in support of their adult offspring's mental health and/or challenging behaviour. This included their experiences of the mental health assessment process and experiences with psychological services. Findings overall revealed more negative than positive experiences with mainstream services reported as lacking in expertise in dual disabilities. Carers also reported difficulties in accessing mental health services and operational and resource limitations of services, all of which serve as barriers to meeting the mental health needs of service recipients. Findings suggested that although carers often expressed uncertainty around the cause of their offspring's changed behaviour, carers were firm in their view on the necessity of timely mental health services and unwavering in their efforts to seek professional help. As suggested in the previous paper of phase three, practical and logistical barriers presented more of an issue for carers compared to any attitudinal barriers to help seeking.

The main causes of dissatisfaction with services related to a lack of consultation and collaboration reported between service providers and carers, limited expertise in dual disabilities of services, limited reasonable adjustments to standard practices, operational and funding limitations and barriers relating to service access. It is interesting to note that a majority of these issues relate to recommendations stipulated in best practice guidelines for services for individuals with dual disabilities. Although there was little awareness and mention of national practice guidelines, carers were clear on the components of an effective service. These findings parallel those from phase two in which psychologists in disability settings shared their views on the components of best practice when working with this specialist population. Findings from this paper will be discussed in context of the outcomes of all six papers in the following discussion section.

Taken together, findings from phases one to three of this research contribute to the intellectual disability literature in the area of psychology clinical practice and attitudes in relation to dual disabilities, organisational facilitators and hindrances to evidence based practice implementation and carer perspectives on services for individuals with dual disabilities. Implications of these findings on clinical practice, service provision and evidence based practice implementation will be discussed in the proceeding general discussion section.

Chapter 8

Thesis Discussion

The aim of this thesis was to investigate Australian psychologists' clinical practices with individuals with an intellectual disability and co-morbid mental health concerns and carer experiences with mental health services. Findings from this thesis are to be understood within the context of Australian service structures with the potential for both national and international implications. Overall, the findings suggest disability service psychologists are cognisant of best practice standards yet experience a number of barriers with practice guideline adherence. Carers generally viewed disability and mainstream mental health services as inadequate and expressed the need for specialist services in dual disabilities. Mainstream mental health services encompassed community health, hospital inpatient and outpatient services as well as private consultations with general practitioners, psychiatrists and paediatricians. Disability services included allied health professionals seen via government and non-government settings as well as accommodation and social and welfare services catered to individuals with an intellectual disability.

Phase One findings revealed that although Australian psychologists reported views and practices that were aligned with international best practice standards, many also expressed limited confidence with mental health diagnosis of individuals with an intellectual disability. This lack of confidence is reflected in carer feedback on service experiences where there was little mention of psychologists playing a role with the assessment of mental health of their child with an intellectual disability. In regards to implementation of best practices, psychologists from both government and non-government disability services reported many systemic barriers hindering evidence based practice adherence, many of which involved difficulties with inter agency and inter disciplinary collaboration and access to appropriate mental health services for individuals with an intellectual disability. This is also consistent with carer encounters with mainstream mental health services of barriers in establishing effective collaborative working

relationships and their limited incorporation of person centred practices. Not only did carers report limited liaisons with service providers, reports of a lack of inter service/ inter disciplinary collaboration and communication were found. These findings parallel those of UK studies on carer experiences where communication and liaison barriers were noted by parents in seeking help from general practitioners (Sayal et al., 2010) and health services (Ali et al., 2013). These findings also align with those from Phase two where disability psychologists reported frustrations with effective collaboration with the health sector in relation to clients with dual disabilities who receive services from both disability and health sectors.

Overall, Phase Two study findings contribute to our understanding of the relationship between current national and international practice guidelines and its implementation into psychology practice by disability service psychologists. Delays between research publication and its filtration into clinical practice is a widely known and long standing issue (e.g., Barbui et al., 2014; Gallo & Barlow, 2012). To assist in bridging the research to practice gap, findings from this phase provide insight into adherence and non-adherence factors concerning evidence based practice implementation in the intellectual disability field which have not been studied previously. This involves highlighting organisational factors which serve to facilitate or hinder evidence based practice implementation and practical barriers experienced by clinicians in adhering to practice guidelines. Furthermore, limited evidence based literature is an issue that is not exclusive to the field of intellectual disabilities. This study provides suggestions on ways in which clinicians can compensate for limits in evidence based practices with use of practice based evidence, drawing on peer consultation, mainstream literature (when none specific to the intellectual disability population are available) and clinical experience and further training. These clinician compensatory practices are likely to be generalisable to other research fields where evidence based practice has yet to be well established. It is likely that practice based

evidence is applicable to other professions in the intellectual disability field such as with psychiatrists via their process of trial and error with psychotropic medications prescriptions as reported by carers in Phase three.

In addition, findings on carer experiences with services for individuals with dual disabilities revealed a general perceived lack in expertise in intellectual disabilities of mainstream mental health services. Carers clearly indicated that specialist services were needed and highlighted the limited availability and barriers in accessing such services. Limited expertise in the disability and health sector in dual disabilities was also reported by psychologists in the disability sector via Phase Two focus groups. These results are consistent with a review of Australian research in mental health and intellectual disabilities which highlighted a lack of training in health professionals and access to health care for people of all ages with an intellectual disability (Torr, 2013). This outcome reflects a systemic issue in limited expertise in dual disabilities which has a flow on effect on service access, service quality, clinical competence and willingness of psychologists and other mental health professionals to service this specialist population.

Carers highlighted both positive and negative experiences in relation to collaborative relationships with service providers and the ability and willingness of services to incorporate special considerations in meeting the individual needs of this specialist population. Carers reported positive experiences with clinicians who consulted them during each phase of service delivery and applied flexibility and person centred approaches with their child with an intellectual disability. Special considerations and reasonable adjustments were clearly found to be important to carers who reported instances when reasonable adjustments were made as well as instances when they were absent. An Australian data linkage study examining mainstream mental health service patterns of individuals with an intellectual disability revealed that people

with an intellectual disability had 1.6 times more face-to-face contacts with total face-to-face contact time 2.5 times longer than people without an intellectual disability (Howlett, Florio, Xu, & Trollor, 2014). This further supports the view of the need for application of reasonable adjustments to individuals with an intellectual disability and their families to address additional service needs.

Carers further reported a number of concerns regarding service access and operational and service resource limitations. These findings parallel reports by psychologists from Phase two where hindrances to evidence based practice implementation involving organisational level hindrances, funding and role limitations were highlighted. Similar organisational barriers to evidence based practice uptake have also been found in a review of mainstream literature examining barriers in human services (Gray, Joy, Plath, & Webb, 2013). Organisational barriers are not exclusive to the psychology profession in relation to barriers to evidence based implementation. Physiotherapists for instance also report organisational barriers during implementation of evidence based treatments for stroke patients (Salbach, Jaglal, Korner-Bitensky, Rappolt, & Davis, 2007). Furthermore, these findings have utility in the context of Australian service models and best practice standards, and are largely consistent with studies on carer experiences with mental health services for individuals with an intellectual disability in the international literature (e.g., Donner, Mutter, & Scior, 2010; Weiss & Lunskey, 2010). Phase three findings further highlight the detrimental impact of funding and resource limitations on service provision as reported by carers with experiences of rejection from mainstream mental health services, pressure from mainstream mental health services for their child with an intellectual disability to be discharged prematurely, and limited reasonable adjustments made to suit the individual needs of the person with an intellectual disability. This implies that although mental health service provision and models in Australia may differ from those in other countries

such as the UK, the barriers reported by carers in accessing person centred services with expertise in both intellectual disabilities and mental health conditions are not unique to the Australian context with many similarities cited with international studies (e.g. Donner et al., 2010).

Phase Three is the first study of its kind to examine mental health literacy in carers of individuals with an intellectual disability. The findings add to our understanding of carer knowledge of mental health disorders and challenging behaviour and their views on how to appropriately respond to these presenting issues. In particular, carers displayed high mental health literacy with depression (74% correct responses) and challenging behaviour associated with autism (84% correct responses). Carers showed less literacy in identifying mixed challenging behaviour and mental health concerns (40% correct responses). Finally, carers reported few attitudinal barriers to seeking help for their child with dual disabilities. Given general practitioners and case managers were rated highly as helpful responses to all vignettes (in Phase 3), support should be provided to assist general practitioners and case managers to make timely and appropriate referrals to mental health services. Moreover, the results from the third phase also highlight difficulties encountered by carers in knowing where to seek help for their child/adult offspring with dual disabilities. General practitioners play an important role in supporting carers to access this information given they are frequently the first port of call in response to presenting problems with their child with an intellectual disability. One reason for this may be due to the Australian Medicare system which enables families to receive rebates for a variety of private services which include private psychiatry and psychology services accompanied by general practitioner referrals. Family support was also viewed by carers as playing an important role in the management of each presenting issue. Given the reported difficulties of carers in finding information on appropriate services, carers should be empowered

to assist the individual with an intellectual disability with easily accessible information on early warning signs of mental ill health and information of referral pathways to appropriate mental health and other support services.

Thesis Implications

Collectively, the results from the three phases of this research suggest the need for improvement in current mainstream mental health and disability services in meeting the needs of individuals with an intellectual disability and their families in Australia. Specifically, these findings have implications for future training, dissemination of national practice guidelines on service delivery to individuals with dual disabilities, utilisation of practice based evidence in contributing to the evidence base in mental health and intellectual disabilities, and incorporating carer involvement into standard practice. These implications will be discussed below.

Training and development.

One major implication of these findings relate to the need for specific training in dual disabilities for both clinical and generalist psychologists as well as a range of professionals who support individuals with dual disabilities. For all mental health professionals, increased knowledge of international and national practice guidelines encompassing special considerations and resources in relation to mental health diagnosis, assessment and intervention is needed across a range of service settings. A recent Australian practice guideline has also laid out core competencies for mental health professionals working with individuals with dual disabilities (Department of Developmental Disability Neuropsychiatry, 2016) based on recommendations stipulated in an Australian practice guideline on servicing individuals with dual disabilities (Department of Developmental Disability Neuropsychiatry, 2014). For mainstream mental health services, the intellectual disability population is only one of many groups of individuals

to whom services are provided. As a result, these services may be less informed in disability legislation and policies, and less aware of the particular service needs of this population group. Hence, special focus needs to be placed on building awareness of disability legislation, evidence based guidelines and reasonable adjustments to improve service accessibility to individuals with an intellectual disability and their carers for clinicians within mainstream mental health services. With the changing nature of disability service provision under the NDIS and the dismantling of state disability services in New South Wales, a body whom previously took on a leadership role in setting benchmarks for best practice no longer exist. In response to this, more centralised training needs to be available to services and continued accountability and upholding of service standards require governance by an external body.

Evidence based practice facilitation.

Findings from Phase Three of the thesis highlight the need for mainstream mental health and disability services to be acquainted with implementation of person centred practices, reasonable adjustments, disability policies and collaboration with other professionals involved in the care of the individual with an intellectual disability. Doing so will enable mental health and disability services to be more accessible and empowering for carers with an intellectual disability. Currently available Australian practice guidelines relating to service delivery for individuals with dual disabilities (e.g. Developmental Disability Neuropsychiatry, 2014) are in its early days of dissemination with many professionals and services yet to be acquainted with these guidelines. For dissemination to be successful, it is recommended that such guidelines be ingrained in federal and state practice and policy with a firm commitment from both health and disability sector leaders to support their integration into practice. Given the organisational barriers noted by psychologists in Phase Two which hinder evidence based practice implementation, it would be beneficial for those in managerial and senior positions within

organisations to be educated on the value of evidence based practice in order to support front line staff with its adherence. Understandably, service providers are often pressured to provide services in a timely and cost-effective manner. Adherence to evidence based practices may not necessarily present as the most cost-effective option despite being the gold standard for practice. Hence, increased government funding and resources to mainstream mental health services is likely to ease the pressure to discharge patients prematurely, reject individuals with an intellectual disability from receiving services, and following standard procedures without consideration of reasonable adjustments to accommodate the specialised needs of individuals with an intellectual disability such as longer and more frequent appointments. For the delivery of disability services under the NDIS, this also has particular relevance since funding will be allocated to provide services based on the minimum standards necessary to ensure adherence to evidence based practices.

Building psychology clinical competency in dual disabilities.

The outcomes from the first two phases revealed that psychologists working in disability service settings tend to hold awareness of best practice principles when working with individuals with dual disabilities. Thus, for psychologists working in the intellectual disability field, it appears that efforts to improve evidence based practice uptake lie not in changing clinician knowledge and views per se but in addressing the systemic and organisational barriers that hinder its uptake. For instance, to combat difficulties with collaboration between services and professionals, inter agency training will assist in fostering better coordination and partnerships and to act in accordance with the New South Wales Memorandum of Understanding (NSW Department of Health, 2010) between the disability and health sector in service provision to individuals with an intellectual disability. Furthermore, the reported limited confidence in mental health diagnosis by psychologists suggests the need to improve clinical

competency in dual disabilities for this profession. Despite some psychologists suggesting their role in mental health assessment is limited, psychologists have a critical role to play in assessing the mental health of individuals with an intellectual disability where their roles are distinct from psychiatrists who are more inclined to treat individuals with more severe psychiatric disorders and prescribe psychotropic medication. Given the limited formal training in intellectual disabilities reported by psychologists during undergraduate and postgraduate psychology training in Australia, this places the onus on psychologists who enter the intellectual disability field to acquire expertise in intellectual disabilities via relevant professional development opportunities. Psychologists' responses in the initial phase of this research highlighted the need for further training specific to their needs which further implies inadequacies in current training opportunities. Online training has been suggested by psychologists as a way to improve training accessibility for those in both metropolitan and rural areas of Australia (Man, Kangas, Trollor & Sweller, 2016) [*Chapter 2*]. Online training is also likely to be welcomed by services looking to minimise costs of professional development activities under the NDIS where funds allocated for a specific clinical service for the individual with intellectual disability are unlikely to cover clinical professional development costs.

Differences in training needs were also reported in Phase One (Chapter 2) with provisional psychologists expressed a need for training in specialised assessment tools while generalist psychologists required training in mental health assessment and treatment people with an intellectual disability, and guidelines on mental health assessment. Clinical psychologists on the other hand expressed a need for online, workshop and conference training formats. These needs should be taken into account when designing training to assist psychologists to increase their knowledge and expertise in assessing the mental health of individuals with an intellectual disability. Furthermore, the training needs of generalist and clinical psychologists are likely to

differ given the differences in professional training in mental health diagnosis. In the context of the NDIS, improving psychology competency in mental health diagnosis for individuals with an intellectual disability will have particular importance in order to secure eligibility for NDIS and funding for services associated with each diagnosis.

Balancing client rights with carer involvement.

One possible reason for carers' reports of collaboration difficulties may be a result of the challenge for clinicians in balancing carer wishes and input with the client's rights to privacy and autonomous decision making. In Phase Three of the thesis, some carers reported collaboration difficulties with service providers as a result of confusion around who is the client and balancing client rights with carer views on treatment. In Australia, all individuals are presumed to hold the capacity for informed decision making unless proven otherwise. Formal guardianship orders are required for individuals over the age of 18 years in order for decisions concerning their supports and wellbeing to be made on their behalf by an appointed legal public guardian (New South Wales Government Attorney General's Department of NSW, 2008). Difficulties arise for adults with an intellectual disability who continue to live with and be supported by their families where legal guardianship was never appointed or required. Thus, for professionals, this can become an issue on occasions where clashes exist between client and family carer views on care provision. As a result, although service providers may apply their best efforts to involve families in decision making for the individual with intellectual disability, ultimately, the final decision rests with the individual with the intellectual disability provided he/she demonstrates ability to make informed decisions. Hence, training for mental health services should also target skills in assisting individuals with an intellectual disability to make informed clinical decisions and to assess their capacity to do so. Clinicians should not assume individuals with an intellectual disability are unable to make such decisions nor should they

avoid involving the family where shared decision-making can be explored. Awareness of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and application of national policies such as the Disability Inclusion Act (NSW Government, 2014), the Capacity Toolkit (New South Wales Government Attorney General's Department of NSW, 2008) and decision making practice frameworks (Bigby, & Douglas, 2015) using a sensitive and supportive manner with the individual with an intellectual disability' best interests in mind can serve to further guide clinical practice. Involving the person with an intellectual disability as much as possible in discussions around their support planning and implementation with their support networks is needed along with a commitment to promote the rights of the person with an intellectual disability (Hillman et al., 2012).

Improving carer accessibility and collaboration with services.

Given findings of carers' high mental health literacy in identifying depression and challenging behaviour associated with autism, this highlights the importance of involving carers as key informants during mental health assessments with individuals with an intellectual disability. Preliminary findings from Phase Three suggest carers are generally cognisant of changes in presentation of their child with an intellectual disability suggestive of mental ill health or challenging behaviour that require clinical attention. Findings from Phase Three suggest that for individuals presenting with depression or challenging behaviour associated with autism, carers may be able to offer accurate assessment information and raise legitimate concerns requiring clinical attention by mental health professionals. These findings need to be interpreted with caution however due to the small sample size and lack of representation from carers with children under 18 years of age. Thus, the role of carers should be valued and utilised given their expert knowledge on the individual with an intellectual disability and their ability to differentiate presenting problems from baseline functioning. Carers also viewed family support

as one of the most important responses to all mental health literacy vignettes further supporting their role as crucial to the wellbeing of their child/adult offspring with an intellectual disability. Improved communication and collaboration between the clinician/service provider and family members of the individual with intellectual disability is even more important under the NDIS where the role of case managers (traditionally playing a mediating role between service providers and families) is currently unknown. In consideration of these findings, carers need to be better supported to 1) access appropriate services in a timely manner, and 2) communicate their concerns effectively to mental health professionals. In addition, mental health services can be supported to 1) collaborate and consult with carers as standard practice, and 2) view carers as important informants and agents of change in relation to the individual with an intellectual disability, inclusive of adults with an intellectual disability. In doing so, this will serve to improve carer satisfaction of services and ultimately lead to better mental health outcomes for the individual with an intellectual disability.

Given mental health clinicians experience difficulties with accurate mental health diagnosis of individuals with an intellectual disability, it is not surprising carers displayed similar difficulties in identifying mixed challenging behaviour and mental health concerns in the third vignette of Phase three of the thesis (Chapter 6). This lends support for mental health assessments for this specialist population being associated with a range of complex considerations requiring specialist knowledge and expertise. Despite the few attitudinal barriers reported by carers in seeking help for their child with an intellectual disability, ambiguity in an individual's presentation may hinder help seeking of carers who may be unclear about the nature of their child's presenting issue and from whom to seek appropriate support. In fact, in previous research, carers with concerns regarding their children's mental health experienced not being taken seriously or listened to by general practitioners, and the possibility of receiving a

diagnosis deterred them from seeking professional help (Sayal et al., 2010). Perceptions of the problem as trivial or temporary, or having difficulty describing the problem was also found to deter mothers of youth and adults with mild intellectual disability in seeking help (Weiss & Lunskey, 2010). Carers with children may also experience this issue given the need to differentiate natural delays in developmental milestones with significant developmental delay likely to lead to an intellectual disability. Encouraging carers to seek supports upon identification of a presenting issue also assists in minimising the risk of untreated problems escalating into unmanageable crises. More accessible services are needed to encourage help seeking behaviours from carers especially at times when the behavioural presentation of their child with an intellectual disability is complex and diagnostically unclear. These findings in addition to experiences of diagnostic uncertainty of mental health professionals reported by carers further suggest the need for future research into increasing sensitivity and specificity of mental health diagnoses of individuals with an intellectual disability and to increase evidence base in mental health assessment for this specialist population.

To assist with mental health diagnosis for this population, adapted diagnostic manuals are available (e.g. Fletcher, Barnhill, & Cooper, 2016). A number of specialist assessment rating scales (e.g., Mohr, Tonge, & Einfeld, 2005; Moss et al., 1998) and adapted mainstream tools (e.g. Singh et al., 2006) to assist with assessing the mental health of individuals with mild to moderate intellectual disabilities are also available. However, continued development of evidence based resources is required to guide mental health diagnosis for individuals with severe and profound intellectual disabilities (e.g. Matson et al., 1999).

Carer supports.

Lastly, to relieve carer burden and isolation, it is recommended that clinicians and case managers support family carers to connect with parent support groups specific to those with a child with a dual diagnosis. However, carers do not always have access to case managers or therapists at the time of onset of mental health symptomology in the individual with an intellectual disability. Information booklets listing a variety of support services including mental health services should be made easily accessible to carers. These could be provided to paediatricians and developmental assessment units upon diagnosis of a child with developmental delay as well as to general practitioner surgeries and services commonly accessed by individuals with an intellectual disability of all ages. Development of online training and psycho-educational resources regarding intellectual disabilities and mental health concerns are also under way in Australia (Department of Developmental Disability Neuropsychiatry, 2013).

Future Research Directions

At present, current gaps in the research literature remain in the area of practice based evidence, implementation of national and international practice guidelines and utilisation and evaluation of specialist services in dual disabilities. Given many of the above recommendations relate to advancement of these areas, it would be important to evaluate whether specialist services and reasonable adjustments to mainstream practice hold added utility in comparison to standard mainstream services and practices. For instance, the use of symbols to accompany simplified written information for individuals with an intellectual disability have not been shown to improve understanding (Poncelas & Murphy, 2007). Findings from the latter study support the need for further research into the application of reasonable adjustments as it is rarely

a one size fits all approach. For instance, research comparing the efficacy of therapeutic modalities modified for individuals with an intellectual disability with mainstream therapeutic programs is required. Given the frequent mention of the need for specialist services, no studies to date have examined carer experiences with Australian specialist services in comparison with mainstream mental health services, and whether such services, 1) offer added clinical utility and expertise, 2) produce better mental health outcomes for individuals with an intellectual disability and their families, 3) result in more positive carer experiences, and 4) display practices in line with international best practice standards. Further examination of these areas are necessary to provide support for continual funding and operation of existing specialist services, increased availability and accessibility of specialist services, and recommendations to improve carer experiences and mental health outcomes for individuals with an intellectual disability.

Practice based evidence is particularly prudent in the intellectual disability field given its heterogeneous nature and high rates of diagnostic co-morbidity (Matson & Williams, 2013; Pickard & Akinsola, 2010). In support of practice based evidence in contributing to the growth of research in the dual disability field, clearer guidelines and protocols are needed regarding its implementation. Practitioner-led research can provide an invaluable contribution to the evidence base in the field of intellectual disability. In fact, there is a growing trend of the utilisation of practice based evidence in the treatment of mental health disorders with efforts to bridge the research and practice gap in the treatment of anxiety disorders (Ollendick, 2014) as well as in counselling services (e.g., Connell, Barkham, & Mellor-Clark, 2007; Evans, Connell, Barkham, Marshall & Mellor-Clark, 2003).

Given the small sample size of carers participating in Phase Three of the thesis, limitations regarding the generalisability of the study's findings to carers across Australia and those from culturally and linguistically diverse backgrounds are noted. Hence, larger samples of

both carers with adequate national and multi-cultural representation are required. Improved representation of a variety of carers, in particular with carers who rarely seek services for their child with an intellectual disability may uncover attitudinal barriers to help seeking which may otherwise have been missed by the small sample in Phase Three. In addition, larger scale studies involving carers with both children and adult offspring with an intellectual disability are needed given potential differences as a result of child developmental and ageing issues. This would enable a more thorough examination of mental health literacy and help seeking barriers in the intellectual disability carer population. Such investigations should also be extended to paid carers supporting individuals with an intellectual disability such as those living in supported accommodation, teachers, respite workers, allied health therapists, and behaviour support practitioners, who provide services to individuals with an intellectual disability. Whether mental health literacy and views on help seeking improve following training in dual disabilities to these groups would also be helpful to uncover to ensure individuals with an intellectual disability who experience mental health concerns receive appropriate and timely supports.

Research involving individuals with an intellectual disability is an important and often neglected area. Hence, future research involving both child and adult individuals with an intellectual disability is needed particularly in relation to service experiences beyond mainstream mental health services such as community services, psychiatric services and psychological services in disability settings where there is a paucity of research.

Furthermore, to ensure successful training outcomes for psychologists, family carers, mainstream mental health and disability services, further research into specific training needs of these groups is needed. In addition, subsequent research in the design, implementation and evaluation of these training programmes is also required. Currently, online training modules are available to a variety of professionals and disability workers in the view of increasing mental

health literacy and expertise in supporting individuals with dual disabilities (Department of Developmental Disability Neuropsychiatry, 2013). However, these training programmes have yet to be evaluated in relation to increased knowledge, attitudes and clinical practice.

Furthermore, there is a paucity of research evaluating training in other formats such as seminars, webinars and workshops designed for specific groups in the intellectual disability field.

Research into the components associated with long term improvements in trainee knowledge, attitudes and work practices will enable more effective training programmes to be designed in the intellectual disability field.

It is hoped that the implications of the outcomes of this thesis will assist in improving access to effective mental health services for individuals with dual disabilities. By paving the way for improved quality of care and mental health service accessibility, this will serve to reduce the detrimental impact of an added mental health disorder for the individual with an intellectual disability and their families.

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APPENDIX G

Published Manuscript (Chapter 2)

Clinical competencies and training needs of psychologists working with adults with intellectual disability and comorbid mental ill health

Joyce MAN,¹ Maria KANGAS,¹ Julian TROLLOR² and Naomi SWELLER³

¹Department of Psychology, Centre for Emotional Health, Macquarie University, ²Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW, Australia, and ³Department of Psychology, Faculty of Human Sciences, Macquarie University, Australia

Key words

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Correspondence

Joyce Man, Department of Psychology, Macquarie University, North Ryde, NSW 2109, Australia.

Email: Joyce.man@students.mq.edu.au

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Abstract

Objectives: Psychologists play a pivotal role in meeting the mental health needs of people with intellectual disabilities. The aim of this study was to investigate the perceptions of Australian psychologists who work with adults with intellectual disabilities and mental ill health regarding their clinical competencies, workplace supports and training needs.

Method: One hundred and nine psychologists in Australia completed a self-report online survey exploring clinical attitudes and practices when working with adults with intellectual disabilities and mental ill health. Provisional, generalist and clinical psychologists from a range of disability and non-disability work settings were recruited.

Results: Findings revealed that provisional, generalist and clinical psychologists reported no significant differences in levels of agreement on self-perceived clinical competencies in conducting mental health assessments. Psychologists in private practice and in non-government organisations reported more adequate workplace resources to support mental health assessments for people with intellectual disabilities than did psychologists in government settings. Psychologists across work settings expressed similar views in self-perceived clinical competencies and workplace training supports. The majority of psychologists reported limited formal academic training in intellectual disabilities and expressed a need for continual and specialised training in mental health and intellectual disabilities.

Conclusions: Implications for further training in mental health and intellectual disabilities highlight the need to cater to the specific needs of psychologists in the field.

Key Points

- 1 Approximately half of the psychologists working in intellectual disability (ID) consider themselves specialists in mental health and ID.
- 2 Psychologists in government disability, non-government and private practice settings reported similar views in clinical competencies in mental health assessment for people with ID and workplace training supports.
- 3 Psychologists report limited formal academic training in ID and a need for continual and specialist training in mental health and ID.

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In Australia, 1% of the population are estimated to have an intellectual disability (ID) (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Studies report prevalence rates of psychological disorders in people, with ID range from 16% (Cooper, Smiley, Morrison, Williamson, & Allan, 2007) to 54% (Gustafsson & Sonnander, 2004), which is much higher than the general population (Cooper et al., 2007). It is therefore imperative that mental health professionals catering to the needs of people with ID are available and accessible. Psychology is one profession considered an essential part of mental health service provision for individuals with ID; hence, it is important to examine psychologists' clinical competencies and training needs given the paucity of research in this field.

Currently, psychological services for people with ID are provided in a variety of settings, including local and community mental health settings, government and non-government disability services. Since November 2006, the Better Access to Mental Health Care Initiative in Australia (Australian Psychological Society, 2007) has increased accessibility to private psychology services. Given the heterogeneous nature of psychological services for people with ID, the ability to provide a timely mental health assessment based on best practice guidelines for a person with ID may be impacted by the work setting of psychologists. For instance, psychologists from public mental health settings and disability services vary considerably in the nature of their contact with people with ID, the length of time available for psychological assessment, the assessment methods employed and the training and experience in mental health and ID (Munden & Perry, 2002). Psychologists in public mental health settings are more inclined to provide acute mental health triage, assessment and short-term individual and group interventions to people without ID. Psychologists working in these settings may hold variable experience in working with people with ID. Psychologists working in disability services primarily provide behavioural assessment and intervention to people with ID. These psychologists may also provide mental health assessment and intervention depending on their training and qualifications.

Psychologists providing mental health care to people with ID have variable professional qualifications. In particular, clinical psychologists and generalist psychologists differ in their professional clinical training. Notably, clinical psychologists in Australia undergo training in the accredited Masters of Clinical Psychology programmes, which emphasise a scientist-practitioner model incorporating in-depth training in assessment, diagnosis and treatment of mental disorders (Australian Psychological Society, 2006). For provisional psychologists undergoing

registration through the Australian Health Practitioner Regulation Agency (four years of undergraduate psychology study plus a further two years of a supervision programme before meeting the requirements as a generalist psychologist), limited guidance exists on integrating the scientist-practitioner model into clinical practice (Psychology Board of Australia, 2013). On this basis, it would be expected that clinical psychologists would exhibit greater confidence in mental health assessments of people with ID and comorbid mental ill health in comparison with generalist psychologists; although this proposition has yet to be empirically substantiated.

In Australia, the study of ID generally forms a small component of the overall curriculum of postgraduate coursework training in psychology. Specialisation in the area of ID is typically established either through disability placement settings during postgraduate training, which are often scarce, or postgraduation via accumulation of clinical contact and experience. Similarly, in the United States, few graduate psychology training programmes offer training in disabilities (Razza, Dayan, Tomasulo, & Ballan, 2014), while Canadian students in graduate psychology training courses report similar difficulty in obtaining adequate didactic and experiential opportunities in ID (Weiss, Lunskey, & Morin, 2010). In comparison, doctoral students in clinical psychology in the United Kingdom are required to complete a six-month placement in a developmental disability community team (Scior et al., 2012). Worldwide, there is limited research that examines clinical competencies of psychologists in the area of ID. It is therefore timely to investigate whether psychologists in this field report sufficient training in the assessment, diagnosis and treatment of people with ID with mental health disorders given the limited formal training opportunities available.

Psychiatry research in comparison has evaluated perceived clinical competencies of psychiatrists working with people with ID. Australian psychiatrists have specifically been found to report receiving inadequate training to address the mental health needs of people with ID (Edwards, Lennox, & White, 2007). The psychiatrists surveyed reported greater competency to identify and treat mental health symptomatology than to diagnose mental health disorders per se (Edwards et al., 2007; Lennox & Chaplin, 1996). On the basis of these findings, the need for specialist training of psychiatrists in ID was highlighted. In response, a fellowship training programme for psychiatric registrars has been offered in NSW, Australia (Johnson, Bowden, Coyne, & Trolor, 2013). An online training module on dual disabilities was also launched offering free training in ID and mental health to all mental health professionals, including psychologists, in Australia (Intellectual Disability Mental

Health e-Learning, 2013). Despite these advances, specialist training for psychologists in ID is not currently widely available in Australia. In comparison, in the United States and United Kingdom, national organisations such as The National Association for the Dually Diagnosed and Estia Centre, respectively, provide further professional training to clinicians on improving mental health provision for people with ID.

In Australia, the National Disability Insurance Scheme (NDIS) is a new insurance-based model of service offering individualised services to individuals with permanent and significant disabilities (National Disability Insurance Scheme, 2014). Given the move towards non-government and private sectors as primary providers of disability services, examining perceived competencies of psychologists in these settings has utility in identifying gaps in training to promote clinical competencies. As mainstream mental health services are not funded under NDIS, it is foreseen that psychologists providing disability services will play a larger role in the provision of mental health services to people with ID, and it is therefore timely to examine current skills and training requirements of psychologists.

Present Study

Given the paucity of studies examining the clinical competencies and training needs of psychologists working with people with ID, the primary aim of this study was to examine psychologists' self-reported clinical competencies and perceptions on adequacy of workplace supports when working with adults with ID and comorbid mental disorders. Differences between psychologists across work settings and the professional roles of provisional, generalist and clinical psychologists were explored. It was hypothesised that due to differences in clinical training in psychology within Australia, clinical psychologists would report greater self-perceived clinical competencies compared to generalist psychologists. The second aim was to explore specialist training experiences and identified needs in working with people with ID. It was predicted that psychologists in general would report a lack of further specialised training in working with this population, and this would apply equally across different work settings and professional qualifications.

Method

Participant Characteristics

A sample of 109 registered and provisionally registered Australian psychologists (91 females, 18 males) who work with adults with ID took part in an online survey.

Table 1 Percentages of demographic characteristics

Groups	<i>n</i>	Percentage of total sample
State (total sample)	109	100
NSW	65	59.63
ACT	4	3.67
Victoria	8	7.34
Queensland	6	5.50
Northern Territories	0	0
South Australia	6	5.50
Western Australia	10	9.18
Tasmania	12	11.01
Work setting (total sample)	109	100
Government disability	62	56.88
Non-government organisation	18	16.51
Private practice	22	20.18
Public health and community health setting	4	3.67
Specialist dual disability service	2	1.83
Other	7	10.09
Qualification (total sample)	109	100
Bachelors	57	52.29
Masters	42	38.53
Other higher qualification	10	9.17
Professional role (Total Sample)	109	100
Provisional psychologist	8	7.34
Generalist psychologist	71	65.14
Clinical psychologist	16	14.68
Other	14	12.84

Notes: Two participants reported working across two states; NSW and ACT. For work settings, some participants worked in more than one setting; hence, % > 100.

All participants completed a minimum of 80% of survey questions, with 17% providing partial responses. Psychologists were recruited from a range of disability and non-disability work settings. The demographic profile of participating psychologists is summarised in Table 1. Psychologists reported extensive clinical experience ($M = 10.55$ years, $SD = 9.31$) ranging from provisional registration to 37 years. The length of stay in current work role also varied ($M = 6.45$ years, $SD = 6$), ranging from 0 to 35 years. Years of experience working with people with ID was similarly extensive ($M = 11.98$ years, $SD = 9.32$), ranging from provisional registration to 42 years. On average, 51% ($SD = 34.37$) of psychologists' caseloads were individuals with ID and mental ill health (range 0–100%).

Measures

Following a literature review and identification of existing gaps in knowledge, a self-report survey was developed exploring clinical attitudes and practices working

with mental health issues in adults with ID. The survey included demographic items on, academic and professional experience in ID, the nature of the clinical contact with people with ID and questions gauging level of agreement, with 25 statements on training, mental health care of adults with dual disabilities, prevalence of mental health concerns in adults with ID and assessment and diagnosis. For the latter, participants were asked to rate the extent to which they agreed or disagreed with each statement on a 5-point scale (ranging from *strongly agree* to *strongly disagree*). A list of common terms with corresponding definitions was provided to familiarise participants with the terminology and ensure the same definitions were used with reference to the statements. Dual disability referred to “individuals diagnosed with both an intellectual disability and a mental health disorders.” Where relevant, the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR) criteria (American Psychiatric Association, 2000) were used to define key terms such as mental disorders and ID given the delays in integrating DSM-5 into clinical practice at the time the study was conducted (2014). The survey also included open-ended questions that asked about perceived training needs of psychologists working with people with ID and suggestions on how training needs could be best met.

Following institutional ethics approval, the questionnaire developed for the purposes of this study was piloted with three psychologists (a generalist, provisional and clinical psychologist) working with people with ID. Following feedback, the questionnaire was revised to improve relevancy of the questions to a range of psychologists. The final version comprised three sections, of which sections one and two are the focus of the current study. Section one included demographic items, and section two consisted of 25 statements and two open-ended items on training. Section three of the survey completed by clinicians who conduct mental health assessments in their current role was excluded from this study.

Procedure

Following review of the questionnaire items and formatting, recruitment for the final online survey occurred by disseminating invitations through a variety of professional networks Australia-wide, including the Association of Psychologists in Developmental Disability Services (PsychDD), Medicare local networks, Australasian Society for Intellectual Disability (ASID) and the Australian Psychological Society (APS), which included the People with Intellectual and/or Developmental

Disability and Psychology interest group. The online survey was developed and disseminated using Qualtrics.

Provisional and fully registered psychologists in Australia who work with adults (over 18 years of age) with ID in their clinical role were recruited. Those working exclusively with children with ID were excluded from the study.

Data Analysis

Descriptive statistics, parametric and non-parametric independent sample *t*-tests and chi-square analyses were used to initially test whether differences emerged between psychologists according to professional roles, provisional, generalist and clinical psychologists, and across work settings. Demographic variables found to significantly differ ($p < .05$) between professional roles and work settings were used as covariate variables in analyses related to specific hypotheses. One-way analyses of variance (ANOVAs) were conducted to examine psychologists' self-reported clinical competencies and perceptions in relation to workplace supports when working with adults with ID and mental ill health (aim one). Four items from the survey were used to examine aim one between professional roles (See Table 2, items 5–8), and two items were used to examine perceived adequacy of resources between workplace settings (See Table 2, items 1 and 8). Ten items from the survey were also used to compare psychologists between work settings (See Table 2, items 1–10). For these post hoc analyses, alpha was set at a more conservative level, $p = .01$, due to the multiple comparisons conducted.

Open-ended questions were used to evaluate the second aim pertaining to perceived training needs of psychologists working with people with ID. Qualitative responses were analysed using thematic analysis and prioritised according to frequency of emerging themes by the first author. The themes generated were then reviewed by the second author for relevancy and consistency. Inter-rater reliability of 20% of qualitative responses was established, with an independent external rater with clinical psychology qualifications (mean Cohen's kappa = 0.78, range 0–1).

Given that the questionnaire items were developed specifically for this study, exploratory factor analysis revealed close to adequate internal consistency, with a Cronbach alpha coefficient reported at .64 for the full 25 items. The questionnaire items were initially structured into four areas: training, mental health care of adults with dual disabilities, prevalence of mental health concerns in adults with ID and assessment and diagnosis; hence, confirmatory factor analyses were conducted to test if items loaded onto these factors. After varimax

Table 2 Significant values for statement comparisons between work settings and professional roles

Statements used in work setting comparisons	F	p	Partial η^2
1. Psychologists in my current work setting receive sufficient on the job training to manage people with dual disabilities	1.54	.220	.036
2. Continual training in dual disability is supported and/or encouraged in my current workplace	1.35	.264	.032
3. Fourth year trained registered psychologists in mainstream mental health services are qualified and skilled in assessing and diagnosing mental health disorders in adults with intellectual disability	.841	.435	.020
4. Fourth year trained registered psychologists in disability services are qualified and skilled in assessing and diagnosing mental health disorders in adults with intellectual disability	1.38	.256	.033
5. I consider myself a specialist in mental health and intellectual disability in my current clinical role	.917	.404	.022
6. I would feel more confident identifying mental health symptoms in adults with intellectual disabilities as compared to making a formal diagnosis of a mental health disorder	.995	.374	.024
7. I have the adequate skills and training to assess and diagnose mental health disorders in adults with intellectual disabilities	2.21	.116	.051
8. I have adequate resources in my current workplace to facilitate assessment and diagnosis of mental health disorders in adults with intellectual disabilities	6.72	.002	.139
9. Disability services can adequately address mental health concerns of adults with dual disabilities	5.30	.007	.113
10. Mainstream mental health services can adequately address mental health concerns of adults with dual disabilities	.222	.802	.005
Statements used in comparisons between professional roles	F	p	Partial η^2
5. I consider myself a specialist in mental health and intellectual disability in my current clinical role	.314	.578	.070
6. I would feel more confident identifying mental health symptoms in adults with intellectual disabilities as compared to making a formal diagnosis of a mental health disorder	.284	.754	.007
7. I have the adequate skills and training to assess and diagnose mental health disorders in adults with intellectual disabilities	2.45	.093	.056
8. I have adequate resources in my current workplace to facilitate assessment and diagnosis of mental health disorders in adults with intellectual disabilities	4.41	.015	.096

rotation, items loaded on four factors. However, as these factors did not appear to relate directly to the prescribed four areas, no further analyses were conducted. Accordingly, individual statements from the questionnaire were used to investigate the study's aims.

Results

Analyses pertaining to participant characteristics were conducted prior to hypotheses testing. Government disability, non-government disability (NGO) and private practice psychologists differed significantly in years of experience as a psychologist, $F(5, 103) = 2.59, p = .030$, partial $\eta^2 = .112$, years of experience in ID, $F(5, 100) = 2.83, p = .020$, partial $\eta^2 = .124$, educational qualifications, $\chi^2(4, n = 92) = 26.85, p < .0005$, and professional role, $\chi^2(6, n = 92) = 17.25, p = .008$ (see Table 3). These variables were therefore included as covariates in subsequent analyses involving work setting (aim one). Given the small proportion of psychologists recruited from public health settings ($n = 4$), meaningful comparisons between psychologists in government disability versus public health settings could not be conducted.

Provisional, generalist and clinical psychologists differed significantly in years of experience as a psychologist, $F(3, 105) = 9.71, p < .0005$, partial $\eta^2 = .217$, years of experience in ID, $F(3, 102) = 4.06, p = .009$, partial $\eta^2 = .107$, years in current work role, $F(3, 104) = 2.72, p = .039$, partial $\eta^2 = .073$, education qualifications, $\chi^2(6, n = 109) = 27.64, p < .0005$, and work setting, $\chi^2(15, n = 109) = 26.19, p = .036$ (see Table 4). These variables were therefore also included as covariates in subsequent analyses when evaluating differences between the professional roles (aim one).

Perceptions on Clinical Competencies

Overall, 65% of psychologists ($n = 68$) reported more confidence in identifying mental health symptoms in adults with ID compared to making a formal diagnosis of a mental health disorder based on DSM-IV-TR criteria (American Psychiatric Association, 2000). However, only half the sample (51%, $n = 54$) reported adequate skills and training to assess and diagnose mental health disorders in adults with ID. Similarly, almost half the sample (49%; $n = 52$) considered themselves specialists in mental health and ID in their current work roles. No

Table 3 Demographic frequencies: psychologists across work settings

	Government disability setting (n = 55)	Non-government organisation (n = 22)	Private practice (n = 15)	p value
Gender				.925
Male	16.36%	13.64%	20%	
Female	83.64%	86.36%	80%	
Professional role				.008
Provisional psychologist	3.64% ^a	22.75% ^b	0% ^a	
Generalist psychologist	69% ^a	63.64% ^a	60% ^a	
Clinical psychologist	12.73% ^{ab}	0% ^b	33.33% ^a	
Other	14.55% ^a	13.64% ^a	6.67% ^a	
Highest professional qualification				<.0005
Bachelors	55% ^a	73% ^a	20% ^b	
Masters	44% ^a	23% ^a	40% ^a	
Higher degree	1% ^a	4% ^a	40% ^b	
	M (SD)	M (SD)	M (SD)	
Years of experience	9.65 (8.85) ^a	9.02 (9.68) ^a	18 (10.5) ^b	
Years of experience in ID	11.31 (8.13) ^a	9.70 (9.24) ^a	20.13 (11.83) ^b	
Years in current role	6.39 (5.86)	5.16 (4.22)	9.47 (8.90)	

Notes: Health settings, specialist settings and other settings were omitted from analyses as sample sizes were too small to make meaningful comparisons. Column means with the same subscript letters (^a, ^b, or ^c) do not differ significantly from each other at the .05 level. Column means with different subscript letters (^a, ^b) differ significantly at the .05 level.

Table 4 Demographic frequencies: comparisons between professional roles

	Provisional psychologist (n = 8)	Generalist psychologist (n = 71)	Clinical psychologist (n = 16)	p value
Gender				.646
Male	12.5%	16.9%	6.25%	
Female	87.5%	83.10%	93.75%	
Highest professional qualification				<.0005
Bachelors	100% ^a	60.56% ^b	0% ^c	
Masters	0%	30.99%	81.25%	
Higher degree	0%	8.45%	18.75%	
Work setting				.003
Government disability setting	25% ^a	53.53% ^a	43.75% ^a	
Non-government organisation	62.50% ^a	19.72% ^b	0% ^b	
Private practice	0% ^a	12.68% ^a	31.25% ^b	
	M (SD)	M (SD)	M (SD)	
Years of experience	0 (0) ^a	10.49 (8.46) ^b	14.19 (10.30) ^b	
Years of experience in ID	3.75 (2.98) ^a	11.90 (9.21) ^b	15.07 (11.04) ^b	
Years in current role	1.69 (0.70) ^a	6.51 (5.75) ^{ab}	8.91 (7.74) ^b	

Notes: Column means with the same subscript letters (^a, ^b, or ^c) do not differ significantly from each other at the .05 level. Column means with different subscript letters (^a, ^b) differ significantly at the .05 level.

significant differences between clinical, generalist and clinical psychologists were found in the above statements (all p 's > .01).

Work setting had a significant effect on perceptions of adequacy of disability services in addressing mental health concerns of adults with dual disabilities, $F(2, 72) = 5.30$, $p = .007$, partial $\eta^2 = .113$. Post hoc pair-wise analyses revealed that compared to psychologists from

NGO settings ($M = 3.29$, $SD = 1.14$), those from government disability settings ($M = 3.85$, $SD = .99$) perceived disability settings as being less adequate in addressing mental health concerns of adults with ID, $F(2, 78) = 9.57$, $p = .006$, partial $\eta^2 = .20$, than did NGO psychologists. However, work setting did not influence psychologist's perceptions of their specialist role in mental health and ID and the adequacy of their skills in

mental health assessment in adults with ID (p 's > .01; see Table 2). Overall, less than one fifth of participants agreed or strongly agreed that four-year trained psychologists in either mainstream mental health (11%; $n = 12$) or disability services (17%; $n = 18$) were skilled in mental health assessment and diagnosis for adults with ID.

Adequacy of Workplace Supports

Forty-three percent ($n = 45$) of psychologists surveyed agreed or strongly agreed with the statement that their work setting provided sufficient on-the-job training in dual disabilities. Similar ratings were found between professional roles and work settings. Work setting had a significant effect on perception of adequacy of workplace resources, $F(2, 72) = 6.72$, $p = .002$, partial $\eta^2 = .139$. Post hoc pair-wise analyses revealed psychologists in private practice ($M = 2.29$, $SD = 0.27$) reported higher agreement ratings on the adequacy of workplace resources for mental health assessment, $F(2, 78) = 10.70$, $p = .003$, partial $\eta^2 = .22$, than did psychologists working in government disability settings ($M = 3.28$, $SD = 1.03$).

Perceived Training Needs

Only 36% ($n = 39$) of participants stated that their academic training included specific training in ID. From the 39 participants who received academic training, 28% ($n = 11$) received a workshop, 41% ($n = 16$) underwent specialist placements, 62% took a course unit/partial course unit in intellectual disabilities, 72% ($n = 28$) received a minimum of a partial lecture and 5% ($n = 2$) received other forms of academic training. In regards to workplace training in dual disabilities, 59% ($n = 64$) attended conferences, 69% ($n = 74$) attended workshops, 78% ($n = 84$) received clinical supervision, 87% ($n = 94$) sought research literature and 11% ($n = 12$) received other forms of workplace training.

The majority of clinicians (86%, $n = 90$) indicated they would like further training in mental health and ID. Common themes were generated amongst four-year and six-year qualified psychologists. Both groups identified online access to training and workshops as the most desirable formats of training. Four-year qualified psychologists also reported assessment and treatment of mental health conditions in adults with ID as an important focus for training. Provisional psychologists identified requiring training in specialised assessment tools, while generalist psychologists required online and workshop formats, assessment and treatment of mental health for people with ID and guidelines on assessment of mental health in people with ID. Clinical psychologists

reported online, workshop and conference formatting as the most important.

Discussion

This study is the first Australian survey exploring clinical competencies and perceived training needs of clinical psychologists compared with generalist and provisional psychologists working in the field of ID. The objective was to investigate the perceptions of clinical competencies and training needs when working with adults with comorbid ID and mental health concerns. Contrary to predictions, clinical psychologists did not rate themselves higher on being a specialist in mental ill health and ID nor in possessing more skills and resources in assessment and diagnosis compared to generalist and provisional psychologists. This is surprising given that clinical psychologists trained in accredited institutions receive specialist formal training in assessment, diagnosis and treatment of mental health disorders and hence would be expected to show more competence in mental health assessment (Newnham & Page, 2010). However, only a small percentage of the sample agreed overall that four-year qualified psychologists are skilled in assessing and diagnosing mental health concerns in people with ID.

Work setting had a significant effect on the perceptions of adequacy of workplace resources in working with adults with ID. Interestingly, psychologists from government disability settings, a work setting assumed to be more resourced, reported lower ratings on the adequacy of workplace resources for mental health assessment and diagnosis of people with ID compared to psychologists working in private practice. It is possible that private practices may be more able to allocate funds to purchase resources, while psychologists from government agencies are dependent on the funding allocated to the organisation and may therefore perceive less control over resource provision. Whether psychologists across work settings differed on their awareness and accessibility to specialist resources is beyond the scope of this article and will be addressed separately.

Psychologists' work setting did not influence perceptions of the specialist role in mental health and ID or perceived adequacy of their skills in mental health assessment in adults with ID. It is unclear how the psychologists surveyed defined the terms "specialist" and "mental health assessment" as these terms were not pre-defined in the questionnaire and are therefore subject to interpretation based on participants' clinical roles within each work setting. Whether this influenced the lack of significant findings will require further investigation. Ratings on the provision of sufficient on-the-job training in ID and comorbid mental ill health were also similar

across work settings. However, it should be noted that psychologists on average rated this item as “neither agree nor disagree,” suggesting that specialist training in mental health and ID may be largely unavailable.

Findings from the second aim supported the hypothesis that psychologists in general receive limited formal training in ID and limited ongoing training in mental health and ID in their current workplace. Importantly, a majority of psychologists (85%) indicated a need for specialist training in this area. Findings suggest that less than half of psychologists surveyed receive some form of academic training in ID, training which varied in depth and duration. This outcome highlights the need for further workplace training in mental health and ID to suit the specific needs of psychologists in the field. At present, diagnostic overshadowing continues to pose barriers to mental health service access for people with ID (Bennett, 2014). It is envisioned that with improved clinical competencies, identification of mental health conditions by psychologists will subsequently improve access to mental health services for people with ID. Given the limited training in ID reported by psychologists within the Australian postgraduate psychology curriculum, specialised training in mental health assessment for people with ID should be an important focus within the workplace. Training in online and workshop formats focusing on mental health assessment and diagnosis incorporating practice guidelines and use of specialised assessment tools for people with ID were identified as necessary by psychologists working in this field. An online training module focusing on the components of mental health assessment for psychologists working with people with ID beyond what has been provided currently via the free online training in dual disabilities (Intellectual Disability Mental Health e-Learning, 2013) would improve access to training for psychologists in both urban and rural areas. Clinical psychologists may also benefit from advanced training in case formulation and mental health diagnosis for people with ID. It is envisioned that with increased specialised training, enhanced clinical competencies and confidence in addressing the mental health needs of people with ID will improve for psychologists working in public mainstream settings.

Study Strengths, Limitations and Implications

Research into the limitations of psychiatry training in Australia has led to many initiatives in an attempt to increase competency in ID such as a competency-based advanced training programme in ID, which was introduced to psychiatric registrars (Johnson et al., 2013). Similarly, it is envisioned that this study has the potential

scope to start the momentum for the development of specialised training of psychologists in mental health and ID. With the Australian NDIS comes the inevitable need to restructure service models and professional roles given the widening scope of consumers meeting criteria for services. Based on the findings of the study, psychologists in general reported limited confidence in the mental health diagnosis of adults with ID and perceived limited adequacy of both mainstream health and disability services in mental health assessment and diagnosis for people with ID. Given this, it is an opportune time to provide advanced training to meet the increased demand for mental health services for people with ID. In fact, strengthening current public mental health services may hold more importance and relevance than developing specialist mental health and ID services (Hemmings, Bouras, & Craig, 2014). Hemmings et al. (2014) suggested that specialists in the field of mental health and ID may be best situated directly within mainstream services rather than operating as separate entities. This model of service may be compatible with the way in which disability services will be delivered under the Australian NDIS.

One limitation of this study is the modest number of psychologists recruited. Although the percentage of registered psychologists in Australia working with adults with ID is unknown, the modest sample size may have compromised the power for group comparisons conducted between professional roles and work settings. For instance, clinical psychologists provided the highest agreement ratings on the self-perceived role as a specialist in ID and mental ill health and rated themselves higher on skills and resources in conducting mental health assessments, and it is likely that higher representation of this group would lead to significant findings. Comparisons between psychologists in public health and disability settings were also not possible due to the small representation of public health psychologists. Furthermore, information on previous work settings was not obtained, and it is possible that participating psychologists may have worked across a variety of work settings, therefore potentially confounding work setting comparisons. Information on the presence of inter-disciplinary teams within current work settings may have impacted psychologists' clinical practices and capacity to collaborate with others.

It was beyond the scope of this article to investigate previous training in ID separate from training in mental health assessment. It is possible that prior training in ID and mental health assessment may impact clinical competence of psychologists conducting mental health assessments with individuals with ID. Furthermore, with all self-report studies comes the limitation of possible

effects of social desirability. It is therefore possible that psychologists motivated to partake in the study may hold special interest in the area of ID and mental ill health and more specialist skills in comparison to other psychologists in this field.

It was beyond the scope of this study to explore how mental health assessments for people with ID are conducted by psychologists and compliance with best practice. This will require further investigation. Given the lack of national guidelines found in Australia, which is similar to the UK and United States, and the heterogeneous nature of qualifications and expertise of psychologists working in ID, it is likely that mental health assessments will vary as a result. How the workplace culture impacts psychologists' perceived clinical competencies given professional role limitations remains unknown. Future studies examining workplace impact on the implementation of best practice of mental health assessment for people with ID would assist in greater understanding of the psychology profession in the evolving field of ID.

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APPENDIX H

Final Ethics Approval Letters



JOYCE MAN <joyce.man@students.mq.edu.au>

RE: HS Ethics Application - Approved (5201300380)(Con/Met)

Fhs Ethics <fhs.ethics@mq.edu.au>
 To: Dr Maria Kangas <maria.kangas@mq.edu.au>
 Cc: Joyce Man <joyce.man@students.mq.edu.au>

Thu, Jul 18, 2013 at 11:39 AM

Dear Dr Kangas,

Re: "An Australian Study of Psychologists' Clinical Attitudes and Practices in Adults with Mental Health Concerns and Intellectual Disability"(5201300380)

Thank you for your recent correspondence. Your response has addressed the issues raised by the Faculty of Human Sciences Human Research Ethics Sub-Committee and approval has been granted, effective 4th July 2013. This email constitutes ethical approval only.

This research meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). The National Statement is available at the following web site:

http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72.pdf.

The following personnel are authorised to conduct this research:

Dr Maria Kangas
 Miss Joyce Yan Yee Man

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Human Research (2007).
2. Approval will be for a period of five (5) years subject to the provision of annual reports.

Progress Report 1 Due: 4th July 2014
 Progress Report 2 Due: 4th July 2015
 Progress Report 3 Due: 4th July 2016
 Progress Report 4 Due: 4th July 2017
 Final Report Due: 4th July 2018

NB. If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Sub-Committee to fully re-review

research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

4. All amendments to the project must be reviewed and approved by the Sub-Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

5. Please notify the Sub-Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

<http://www.mq.edu.au/policy>

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of approval to an external organisation as evidence that you have approval, please do not hesitate to contact the Ethics Secretariat at the address below.

Please retain a copy of this email as this is your official notification of ethics approval.

Yours sincerely,

Dr Peter Roger
Chair
Faculty of Human Sciences Ethics Review Sub-Committee
Human Research Ethics Committee

Faculty of Human Sciences - Ethics
Research Office
Level 3, Research HUB, Building C5C
Macquarie University
NSW 2109

Ph: +61 2 9850 4197
Fax: +61 2 9850 4465

Email: fhs.ethics@mq.edu.au



JOYCE MAN <joyce.man@students.mq.edu.au>

RE: HS Ethics Application - Approved (5201400983)

Fhs Ethics <fhs.ethics@mq.edu.au>

Thu, Oct 30, 2014 at 12:29 PM

To: Associate Professor Maria Kangas <maria.kangas@mq.edu.au>

Cc: Dr Naomi Sweller <naomi.sweller@mq.edu.au>, Julian Trollor <J.Trollor@unsw.edu.au>, Ms Joyce Man <joyce.man@students.mq.edu.au>

Dear Associate Professor Kangas,

Re: "Implementation of best practice mental health assessment for people with intellectual disabilities: The Impact of Work Settings"(5201400983)

The above application was reviewed by The Faculty of Human Sciences Human Research Ethics Sub-Committee. The Faculty Ethics Sub-Committee wishes to thank you for your well-written application. Approval of this application has been granted, effective 30th October 2014. This email constitutes ethical approval only.

This research meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). The National Statement is available at the following web site:

http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72.pdf.

The following personnel are authorised to conduct this research:

Associate Professor Maria Kangas
Dr Naomi Sweller
Julian Trollor
Miss Joyce Yan Yee Man
Ms Joyce Man

NB. STUDENTS: IT IS YOUR RESPONSIBILITY TO KEEP A COPY OF THIS APPROVAL EMAIL TO SUBMIT WITH YOUR THESIS.

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Human Research (2007).
2. Approval will be for a period of five (5) years subject to the provision of annual reports.

Progress Report 1 Due: 30th October 2015
Progress Report 2 Due: 30th October 2016
Progress Report 3 Due: 30th October 2017
Progress Report 4 Due: 30th October 2018
Final Report Due: 30th October 2019

NB. If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

4. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

<http://www.mq.edu.au/policy/>

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of approval to an external organisation as evidence that you have approval, please do not hesitate to contact the FHS Ethics at the address below.

Please retain a copy of this email as this is your official notification of ethics approval.

Yours sincerely,

Dr Anthony Miller
Chair
Faculty of Human Sciences
Human Research Ethics Sub-Committee

Faculty of Human Sciences - Ethics
Research Office
Level 3, Research HUB, Building C5C
Macquarie University
NSW 2109

Ph: +61 2 9850 4197
F: +61 2 9850 4195

Office of the Deputy Vice-Chancellor
(Research)

Research Office
Research Hub, Building C5C East
Macquarie University
NSW 2109 Australia
T: +61 (2) 9850 4459
<http://www.research.mq.edu.au/>
ABN 90 952 801 237



MACQUARIE
University
SYDNEY • AUSTRALIA

23 October 2015

Associate Professor Maria Kangas
Department of Psychology
Faculty of Human Sciences
Macquarie University
NSW 2109

Dear Associate Professor Kangas

Reference No: 5201500759

Title: *Family carer experiences of mental health services, knowledge and help seeking for people with intellectual disabilities*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) at its meeting on 25 September 2015 at which further information was requested to be reviewed by the HREC (Human Sciences and Humanities) Executive.

The requested information was received with correspondence on 7 October 2015. The HREC (Human Sciences and Humanities) Executive considered your responses at its meeting held on 13 October 2015. The Executive requested further information to be reviewed by the Ethics Secretariat.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

This letter constitutes ethical and scientific approval only.

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.
3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.
4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely



Dr Karolyn White
Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Details of this approval are as follows:

Approval Date: 23 October 2015

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
Correspondence from Ms Joyce Mann responding to the issues raised by the HREC (Human Sciences and Humanities)		Received 7/10/2015
MQ Participant Information and Consent Form (PICF): Phase 1	1	September 2015
MQ Participant Information and Consent Form (PICF): Adult with intellectual disabilities Phase 2	1	September 2015
MQ Participant Information and Consent Form (PICF): Carer Phase 2	1	September 2015
Informal email to networks		
Advertisement for PsychDD newsletter		
Flyer for recruiting carers		
Participant Questionnaire		
Interview questions		