

# Using easy read information about mental health for people with intellectual disability

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Using easy read information about mental health for people with intellectual disability

Bronwyn Newman

A thesis in fulfilment of the degree of  
Doctor of Philosophy



Social Policy Research Centre  
Arts and Social Sciences  
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February 2020



## Thesis/Dissertation Sheet

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**Background:** Access to information is a right articulated in the United Nations Convention on the Rights of Persons with Disability that remains unrealised for many people with intellectual disability. Information access, including the provision of Easy Read documents, is one strategy recommended to address the widely recognised inequity in mental health outcomes and service access for people with intellectual disability. This research explores how easy read information about mental health is used to make mental health information more accessible for people with intellectual disability.

**Method:** A mixed methods study was undertaken which included policy analysis, resource mapping and semi-structured interviews. Australian and New South Wales (NSW) State and Local Health District mental health policy documents were reviewed (N=66). Semi-structured interviews were conducted across four sites in Sydney NSW to explore how easy read was used. Participants (N=49) included people with intellectual disability, their carers/families, advocates and mental health staff. The activities of accessing, understanding, appraising and applying information as defined in Sprensen et al.'s integrated health literacy framework were used to analyse the data.

**Findings:** Mental health policy rarely incorporated communication strategies for staff to use when working with people with intellectual disability, despite agency commitment to the principle of accessible information. Easy read was one of several strategies people used to make information easier to understand and assist people with intellectual disability to appraise and apply information. Relationships between people with intellectual disability, family or carer and service providers affected information access for people with intellectual disability. Most mental health staff did not use accessible information and did not consistently offer people with intellectual disability opportunities to understand, appraise and apply mental health information.

**Implications/Significance:** People with intellectual disability did not routinely have access to mental health information, confirming that agencies are not meeting their obligations to provide accessible information. Enabling information access requires urgent systemic change, so that staff attitudes, service agency policy and structures uphold the right to information. Inclusive research about using easy read in health contexts, including mental health, is needed to facilitate change.

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## Abstract

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**Background:** Access to information is a right articulated in the United Nations Convention on the Rights of Persons with Disability that remains unrealised for many people with intellectual disability. Information access, including the provision of easy read documents, is one strategy recommended to address the widely recognised inequality in mental health outcomes and service access for people with intellectual disability. This research explores how easy read information about mental health is used to make mental health information more accessible for people with intellectual disability.

**Method:** A mixed methods study was undertaken which included policy analysis, resource mapping and semi-structured interviews. Australian and New South Wales (NSW) State and Local Health District mental health policy documents were reviewed ( $n=66$ ). Semi-structured interviews were conducted across four sites in Sydney NSW to explore how easy read was used. Participants ( $n=49$ ) included people with intellectual disability, their carers or families, advocates and mental health staff. The activities of accessing, understanding, appraising and applying information as defined in Sørensen et al.'s integrated health literacy framework were used to analyse the data.

**Findings:** Mental health policy rarely incorporated communication strategies for staff to use when working with people with intellectual disability, despite agency commitment to the principle of accessible information. Easy read was one of several strategies people used to make information easier to understand and assist people with intellectual disability to appraise and apply information. Relationships between people with intellectual disability,

family or carer and service providers affected information access for people with intellectual disability. Most mental health staff did not use accessible information and did not consistently offer people with intellectual disability opportunities to understand, appraise and apply mental health information.

**Implications/Significance:** People with intellectual disability did not routinely have access to mental health information, confirming that agencies are not meeting their obligations to provide accessible information. Enabling information access requires urgent systemic change, so that staff attitudes, service agency policy and structures uphold the right to information. Inclusive practices, that incorporate using easy read in health contexts, including mental health, are needed to facilitate change.



### **Why we researched about using easy read mental health information**

People with intellectual disability often miss out on getting the mental health information and mental health services they need. People with intellectual disability, their families and supporters have said that it would be helpful to have more easy read mental health information. Easy read information is made for people with intellectual disability. This research is about how people use easy read information about mental health.

### **How we did the research**

The research had three parts.

First, we looked at all Australian and NSW government policy about mental health find out what the rules are about giving people with intellectual disability health information. The review included 66 policies.

Second, we asked mental health staff, people with intellectual disability, their carers, families and advocates about how they used easy read. 49 people from 4 agencies were interviewed. One agency was an advocacy service and the other three were mental health services.

Third, we summarised what the easy read or accessible information that staff used at their agencies was used for.

### **What we learned about using easy read mental health information**

This research found five main things.

- Mental health policy said that all people have a right to information but most policy did not have instructions about how to communicate clearly with people with intellectual disability.
- The mental health agencies did not have much accessible information. Most mental health staff had not used easy read.
- Only the agencies specialised in working with people with intellectual disability often used accessible information and easy read. The people with intellectual disability and the staff who used easy read said it was very useful.
- Most mental health staff did not think people with intellectual disability were given enough information or time to make decisions about mental health information.
- Whether or not easy read was available was only one part of making information accessible. The relationships between people with intellectual disability, their families or carers and service providers also affected how people made decisions about their mental health information.

### **Agencies need to make mental health information more accessible**

People with intellectual disability did not usually have access to mental health information, even though the law said they should. Mental health agencies need to make changes now so that people with intellectual disability have the information they need. Mental health agencies need to make sure people with intellectual disability can have information like easy read. They need enough time to ask questions. They need support to understand information. It is important to do more work with people with intellectual disability to know how to make mental health information easier to find and use.

## Presentations

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Newman, B. (2019) *Easy read: using it well*, webinar presented for the *Australasian Society of Intellectual Disability* (ASID), 25 September 2019, available at:

<https://www.asid.asn.au/publications/webinars>.

Newman, B. (2018) *How is the right to accessible information represented in Australian mental health policy? Let's Shake it Up – human rights for everyone*. Australian Association for Intellectual Disability Conference, 14-16 November 2018, Gold Coast Convention Centre, Queensland Australia.

Newman, B. (2018) *How is easy read Information about mental health used to enable access to information?* A&SS PG Conference Headways: Progress and New Directions in the Arts and Social Sciences, 20 July 2018, UNSW Sydney

Newman, B. (2018) *How can easy read documents be used to make information about mental health more accessible?* Poster Presentation. International conference on communication in healthcare. September 1 - 4, 2018 University of Porto, Porto, Portugal.

Newman, B. (2018) *How is easy read Information about mental health used to enable access to information?* Oral presentation Mental Health Drugs and Alcohol research conference, 2 August 2018, Macquarie Hospital, Ryde, NSW, Australia

Newman, B. (2017) *The right to accessible information about mental health for people with intellectual disability: how is it represented in policy?* Grand Challenges Postgraduate Conference, 20<sup>th</sup> July 2017, UNSW Sydney.

Newman, B. (2016) *Accessible information for people with Intellectual Disability about Mental Health: what do we know?* Social workers in Disability Conference: *Maximising*

*Diversity, Engagement and Inclusion in 2016*, 24 November 2016, University of Western Sydney, Penrith.

Newman, B. (2016) NGO Research Forum: Facilitated Workshop, *Accessible information for people with intellectual disability about mental health: relationship to social inclusion*, 24<sup>th</sup> August 2016, Sydney.

## Publications

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Newman, B. (2019), 'The responsibility of making information accessible', *Intellectual Disability Australasia (IDA)* magazine, vol 40, no. 2, 2019 pp. 6-9, available at <[https://www.asid.asn.au/files/2680\\_ida\\_volume\\_40\\_issue\\_2\\_june\\_2019.pdf](https://www.asid.asn.au/files/2680_ida_volume_40_issue_2_june_2019.pdf)> .

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## Preface

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Working in the disability sector as a social worker brought me into contact with many people with disability who experience restrictions in their participation in community life. This included access to basic activities of life such as education, healthcare and employment. Often people with disability, particularly intellectual disability, were given limited access to information and this impacted their decision-making. I witnessed that community attitudes and structures denied some people the 'inherent dignity' and 'equal and inalienable rights of all members of the human family' described in the preamble of the United Nations declaration of human rights (United Nations General Assembly, 1948).

The experience of walking beside people who were denied the rights that many 'non-disabled' community members enjoyed heightened my awareness of the disparities that people with intellectual disability lived with. While the United Nations Convention on the Rights of Persons with Disabilities had been ratified by Australia, it was evident that the rights it articulates were not always realised for this group (United Nations, 2006) .

Understanding that access to information is a right that agencies and staff (including me) have an obligation to provide was an uncomfortable reality.

The default position often represented in agency practices was that people with intellectual disability are not capable, not interested, or would find information or choice to be overwhelming. I saw that limited access to information not only violated the right to accessible information, but also had far reaching consequences for people with intellectual disabilities and their families or carers. These experiences fuelled my interest in accessible information and a desire to understand more about how easy read information about health can be used.





## Thesis outline

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This thesis has 9 chapters. Background information is presented, followed by methods, findings, discussion and implications.

Chapters 1 and 2 present background information to the thesis. Chapter 1 presents an introduction with a focus on the changing attitudes towards disability and accessible information. Chapter 2 presents a scoping review of the literature and includes a summary of what is known about using accessible information about mental health when working with people with intellectual disability. Chapter 2 finishes with a list of research questions to frame the research.

Chapter 3 details the methodological approach and overarching methods used in this research.

The findings are presented in 4 chapters, starting with Chapter 4: Policy Analysis. The policy analysis findings inform the chapters which follow. Findings from interview data are organised in chapters to correspond with the concepts of accessing, understanding, appraising and applying information as described in Sørensen et al.'s integrated health literacy framework (Sørensen et al., 2012).

Each interview findings chapter commences with a brief vignette written from the interviews with people with intellectual disability. Chapter 5 focuses on how information is accessed at mental health agencies, and the agency structures in place to meet their obligation to provide information. Chapter 6 explores how people with intellectual disability used easy read to make information understandable, and the ways that agencies adapt

information to make it more understandable. The final findings chapter, Chapter 7, analyses the ways that easy read information was used to appraise and apply health information.

Chapter 8 presents a discussion of the findings to address the research questions, and explores the implications for theory and practice. This chapter considers the relevance of the findings for service users, providers and policy makers.

Chapter 9 is the concluding chapter of this thesis. It offers some reflection on the implications of the availability of accessible information about mental health, agency responsibility and the realisation of the UNCRPD for people with intellectual disability.

The 21 appendices contain detailed information pertinent to this research, including examples of data collection tools.

## Terms used

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*Accessible information:* in this thesis the term ‘accessible information’ refers to the broad suite of strategies used to enable understanding by people with intellectual disability (Mander, 2016). This definition of accessible information includes strategies such as easy read. Researchers and service providers still use this term in various ways, however the literature reveals an emerging consensus which this definition reflects.

*Agency:* with a capitalised A, this word is used to denote the agencies participating in this research. Agencies are numbered 1-4 and are described in Chapter 3.

*Easy read:* the term ‘easy read’ is used to describe text-based documents designed to make information easier for people with intellectual disability to understand. Easy read documents most often contain a combination of pictures and simple text. They generally contain large font, simple language and images in various formats (Sutherland & Isherwood, 2016). Hurtado et al. state that the term easy read ‘refers to constructing information in a way that is easy for the recipient to understand and it exceeds simply making the vocabulary and grammar simpler’ (Hurtado et al., 2014, p. 823).

The literature was inconsistent in describing the specific design and characteristics of easy read and there is no standard terminology within Australia or internationally. Other terms commonly used are ‘Easy English’ or ‘Easy to Read’.

*Families or carers:* describes the people who support people with intellectual disability to access health services. This includes parents, relatives, friends or significant others.

*Intellectual disability*: The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) is commonly used as a reference tool by psychiatrists and medical practitioners.

The DSM-5 definition of intellectual disability has been used.

It states that intellectual disability must begin during the developmental period and impacts adaptive functioning in three domains. These domains are defined as:

- Conceptual: this domain ‘includes skills in language, reading, writing, math, reasoning, knowledge, and memory’.
- Social: ‘refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.’
- Practical: ‘centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks’.

(American Psychiatric Association, 2013).

‘Intellectual disability’ is a term commonly used in Australia, however there are several other terms commonly used internationally to describe intellectual disability. Intellectual disability is referred to as ‘intellectual impairment’ by the World Health Organisation and ‘also known as, *learning disabilities, learning difficulties, and formerly as mental retardation or mental handicap*’ (World Health Organization, 2011, p. 305).

*Integrated health literacy framework*: Sørensen et al.’s (2012) integrated health literacy framework is used to analyse this research. The activities of accessing, understanding, appraising and applying health information are a focus of this thesis. Chapter 1 explains further detail about the framework.

*Local Health Districts (LHD)*: NSW is divided into fifteen geographical Local Health Districts or LHDs. Each LHD is responsible for managing public hospitals and health institutions and providing health services (NSW Health, 2014).

*National Disability Insurance Scheme (NDIS)*: The National Disability Insurance Scheme (NDIS) commenced in Australia in 2016 and is available in all states in 2019. The scheme is jointly funded by Commonwealth and territory governments to support people with disability, their families and carers. The NDIS is administered by the National Disability Insurance Authority (NDIA).

The NDIS has a role in helping all people with disability access mainstream and community services and maintain informal supports. Non-means tested individualised packages of support are the main component of the NDIS, available to approximately 10% of people with disability (Parliament of Australia, 2017). The NDIS packages can include funding for transport to enable participation in community or daily life activities, employment assistance, therapeutic supports, mobility equipment and home modification (NDIS, 2018; Parliament of Australia, 2017).

Eligibility for an NDIS package is based upon meeting citizenship requirements and being under the age of 65 at the time of application. The NDIS website states that to be eligible, recipients must have a developmental delay or lifelong, permanent disability that significantly affects their ability to take part in everyday activities (NDIS, 2019b).

*Participants*: is used to describe all interviewees. This group includes people with intellectual disability, carers – paid and unpaid – and staff in both frontline and managerial roles.

The following terms are a more detailed description of participant roles or characteristics.

These are used to attribute direct quotes and to maintain participant anonymity:

*Advocacy and support staff:* staff whose primary responsibility is to support people with intellectual disability to access services.

*Allied health:* psychologists, social workers, dieticians, occupational therapists, youth workers and exercise physiologists.

*Manager:* includes service managers unless a separate discipline was identified. For example, Nursing manager.

*Medical practitioners:* includes psychiatrists, psychiatry registrars, paediatricians and paediatric registrars.

*Nursing:* registered nurses in roles at inpatient and community-based agencies. The participants had varying experience working with people with intellectual disability. Some had been trained in mental health nursing overseas and in Australia, while others had not completed any specialised mental health training.

*Other:* admin staff, evaluation staff and peer support staff.

*Service Users:* people with intellectual disability who used Agency 4 services.

*Specialist Intellectual disability consultant:* staff member employed to provide support to staff working with people with intellectual disability.

*Personalised care:* centres around people having choice and control over the way their care is planned and delivered (National Health Service n.d).

*Recovery-oriented mental health practice:* offers strategies that support service-users to take responsibility for their own well-being. Recovery-oriented practice recognises individual capacity, maximises self-determination and management of mental health, and

supports families of people accessing mental health services (Commonwealth of Australia, 2013).

*Staff*: the paid staff at participating Agencies who participated in interviews. This includes staff in frontline and managerial roles.

*Trauma informed care and practice (TICP)*: is a strengths-based framework that recognises the impact of past trauma and potential for further traumatisation in mental health service settings. The framework emphasises 'physical, psychological, and emotional safety for both service providers and survivors; and creates opportunities for survivors to rebuild a sense of control and empowerment' (Mental Healthcare Commission, 2014).

Checklists have been developed to assist mental health service providers to implement TICP across varied intervention models.

## CHAPTER 1: BACKGROUND

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This research about easy read is founded on the rights of people with intellectual disability, particularly the right to health information. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) states that all people have a right to health information (Articles 9, 21 and 25). In Australia and internationally, health information is acknowledged to be difficult for people with intellectual disability to access, despite the ratification of the UNCRPD. This limited access to health information has significant implications for people with intellectual disability as this group is known to experience poorer health outcomes than other people in the community (Govett et al., 2013; Evans et al., 2012; Tonge et al., 2013).

The health service environment can be particularly problematic for people with intellectual disability. People with intellectual disability often experience difficulty learning, applying knowledge and making decisions; almost 60% of people with intellectual disability have severe communication limitations (Australian Institute of Health and Welfare (AIHW) 2008). Over half a million Australians have intellectual disability and a majority (61%) of those people have a severe or profound limitation in 'core' activities of daily living. People with intellectual disability are a major group of users of disability support services in Australia (AIHW 2008). It is recognised that people intellectual disability are more likely to experience



mental ill-health, with common mental disorders occurring around two to three times more frequently than the general population (Cooper et al., 2007; Evans et al., 2012.)

This introductory chapter explores background information to characterise the experience of people with intellectual disability accessing mental health information, outline the available evidence about using easy read, and situate the research in current scholarship.

This research seeks to address the disconnect between evidence about easy read and what happens in practice . The focus of this research on easy read information about mental health straddles several areas of knowledge. It rests upon existing understanding of rights, the backdrop of mental health and intellectual disability support, accessible information and health literacy. The first section of the chapter focuses on history, rights, and the current service landscape as a foundation for the second half of the chapter. The second half of the chapter explores information access, exposes gaps in knowledge about easy read, and introduces the integrated health literacy framework.

## 1.1 Rights unrealised

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The recognition of the right to information for people with intellectual disability is a relatively recent manifestation of more significant changes to the way that disability is understood. Intellectual disability service provision has undergone momentous change over recent decades in Australia and internationally (Shakespeare, 2014). Current practices are characterised by inclusive service models founded upon on the rights of people with intellectual disability to make decisions about how they live their lives, but this was not the case historically (Kayess & French, 2008). Despite significant changes to practice, the right to both mental health information and service access remains unrealised for many people with

intellectual disability (Whittle et al., 2018; Venville et al., 2015; Chinn, 2016b). This section explores past practices and the United Nations Convention on the Rights of Persons with Disability (UNCRPD, 2006), before examining the current service landscape.

#### 1.1.1 Considering the past

People with intellectual disability and people who experienced mental ill-health have until recent years been pushed to the margins of society, and this continues to impact current attitudes. Historically, beliefs about disability and mental illness were reflected in policies and practices which promoted seclusion from society. Policy which regulated care and support was reflective of, and reinforced, exclusionary community attitudes that did not require or anticipate that people with intellectual disability would take part in knowledge exchange or decision making. People with disability were seen as 'objects of welfare, health and charity programs' (Kayess & French, 2008, p. 14) rather than citizens who wished to engage in society. Past policies and practices provide insight into an era in which accessible information for people with intellectual disability was not a consideration.

#### *Segregation*

Historically, life for people with intellectual disability and people who experienced mental illness most often involved segregation from community in the family home or in an institution. At the time of European settlement in Australia, exclusion most often took the form of placement in an asylum which housed people of varying ages and needs, and which met all daily needs (Malcolm, 2010; MacKinnon & Coleborne, 2003). A duty to maintain order and offer protection motivated policy makers and service providers. Moral responsibilities underpinned this exclusion, rather than a physiological or medical understanding of the conditions faced by 'inmates' or a desire to heal or engage with individual needs (Bracken, 2015; Foucault, 1988, p. 46). Information access for asylum

inmates was not a consideration. There was little delineation in service options or treatment available to people with intellectual disability or people experiencing mental ill-health. The desire to protect both the weak from the community, and to protect the community from people who may cause harm, was the primary driver for this approach.

The discovery of medications to subdue or treat mental health conditions during the 1950s revolutionised care and increased the distinction between mental health conditions and intellectual disability (Cawte, 1998). The nature of institutions changed, with greater delineation of services according to diagnosis, but exclusionary service models remained (Coleborne, 2001, p. 108). Increasingly, health facilities and hospitals offered treatment for patients with mental ill-health while people with physical and intellectual disabilities resided in other institutions. The increase in medical treatment options for mental ill-health reinforced the perception of intellectual disability as an incurable condition, requiring lifelong care and protection (Coleborne, 2001; Finnane, 1985). This historic delineation of care created inflexible service boundaries which further complicated access to services for people with intellectual disability who experienced episodes of mental ill-health (discussed further in Section 1.2).

### *Information access*

A history of institutional care sets the backdrop for a recent past which has a lingering impact on many aspects of service provision, including the need for information. The use of large congregate models of care reflected a view of people with intellectual disability that did not recognise their ability, desire or right to make choices. The work of Erving Goffman (1961) gave a unique insight into life within the large institution as well as information access, and this continues to be relevant. The key features of the institution, as articulated

by Goffman, were that 'all aspects of life [were] conducted in the same place and under the same single authority'. Each phase of life was lived with a 'batch' of others and daily life was tightly scheduled with activities to suit institutional aims (Goffman, 1961, p. 6). The perception of people with intellectual disability as passive recipients of care, people to provide protection to or protect from, negated any sense that information about health or services was of value to this group (Finnane, 1985).

The transition away from large congregate service models seen since the 1960s did not guarantee inclusion in decision making, or information access for people with intellectual disability. The lack of consideration for individual needs continued to be an issue, despite significant policy change, and can be attributed to both attitudes and agency practices. Historic attitudes about the need to protect people with intellectual disability were evident in policy, service models and the views of families and carers throughout the transition from institutional to community-based care (Tøssebro & Lundebj, 2006). Wolfensberger (1972) reasoned that it is in fact agency or organisational processes which result in 'de-individualisation', and that these are not only attributable to the size of residential services. Whether in large congregate care or smaller community settings, service providers can prioritise agency goals and efficiencies over individual need, with a '*batch*' approach to service users (Goffman, 1961). Advocates and researchers have shown that choices for some people with intellectual disability continue to be limited and governed by others (Commonwealth of Australia, 2009).

### 1.1.2 UNCRPD

The United Nations Convention on the Rights of Persons with Disability (UNCRPD) was a monumental turning point in the recognition of the rights of people with disability to

participate in community life (Kayess and French, 2008). Australia ratified the Convention in 2008 and the optional protocol of the UNCRPD in 2009 (Australian Law Reform Commission, 2013). The Convention recognised a fundamental attitudinal shift from the historic stance of exclusion and welfare-based actions to a rights-based framework for understanding disability.

The UNCRPD defines disability as:

the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others

(United Nations, 2006).

This definition captures current conceptualisations of disability, traversing the traditional divide between medical and social constructions of disability. Traditional conceptualisations of disability focus on individual impairment requiring ongoing intervention or care, whereas social constructions of disability emphasise community features or social structures as disabling (Shakespeare, 2014). The UNCRPD states that people with disabilities have a right to accessible information to enable participation in community life (United Nations, 2006).

The universalist approach presented in the UNCRPD redefined difference as ‘probable’ rather than exceptional and resulted in greater awareness of the need for inclusive community design (Kayess and French, 2008). The Articles with direct relevance to information access and decision making are examined in the Policy Analysis (Chapter 4).

The UNCRPD recognises the right to healthcare services without discrimination and for agencies to make appropriate accommodations (Article 25), but this is often not the experience of people with intellectual disability. The UNCRPD states that people have a right

to accessible information which agencies have a responsibility to provide, and this includes information about health. Kayess and French (2008) argue that making reasonable accommodations is a crucial equality measure, stating that agencies have a responsibility to alter the 'norm to better reflect human diversity' (Kayess and French, 2008, p. 9). The current statistics about mortality, morbidity, health service access and use for people with intellectual disability in Australia and abroad reveal significant disparities between people with intellectual disability and the broader population, as described in Section 1.2. This is even more the case for people with intellectual disability who are known to experience difficulties accessing appropriate mental health services in Australia and internationally (Venville et al., 2015; Whittle et al., 2018).

## 1.2 Problematic service landscape

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The changes precipitated by the UNCRPD have not resulted in equitable service access or health outcomes for all people with intellectual disability. The historic division between disability and health services makes access to mental health services difficult for people with intellectual disability. Many people with intellectual disability and mental ill-health experience ongoing difficulties accessing services despite significant reform (Whittle et al., 2018; Venville et al., 2015). Past attitudes, continued confusion surrounding the needs of people with intellectual disability, and inadequate funding and support continue to impact access to services (Venville et al., 2015; MacKinnon & Coleborne, 2003; Bigby & Fyffe, 2006).

In Australia most people with intellectual disability and co-occurring mental ill-health can access services via the National Disability Insurance Scheme (NDIS), and from the mental health service system. This division between health and disability services is difficult for

many people to navigate (Commonwealth of Australia, 2019). This section of the chapter first presents information about the NDIS, then mental health services, and concludes by focusing on the role of accessible information in personalised service models.

### 1.2.2 The National Disability Insurance Scheme (NDIS)

The NDIS is the primary platform for funding of disability support needs for people with disability in Australia (Parliament of Australia, 2017). The NDIS has a role in supporting all people with disability to access mainstream services such as health, education and community activities. The scheme aims to deliver a comprehensive, individualised approach to service provision for eligible people with disability, including people with intellectual disability who experience mental ill-health (see Terms used, p. 12). It represents a fundamental change to the way that disability services are provided and reflects Australia's commitment to the UNCRPD (NDIS, 2018). The NDIS was designed to simplify service access and deliver opportunities for people with various disability types to access greater choice and control in how their needs are met.

The NDIS was developed in response to the Productivity Commissioner's Report (2011) which highlighted the complexities and shortcomings of the disability services sector (see Chapter 4 for further detail about policy). The NDIS is a marketised system, where the commitment to greater choice and control is reflected in the direct allocation of funds to people with disability as a main component of the scheme (NDIS, 2018). The allocation of funds gives the service user choice about where they access the support they need, and simultaneously shapes the market by creating demand (Mladenov et al., 2015).

The NDIS rollout began in July 2016 and the scheme is now available in all Australian states and territories (National Disability and Carer Alliance, 2018). In September 2019 over 314

000 people had accessed the scheme and for over 114 000 people this was the first time they had accessed services (NDIS, 2019a). When the rollout is complete, 460 000 people, which equates to approximately 10% of people with disability, will have access to individualised NDIS packages (Parliament of Australia, 2017). The NDIS brings great promise to many who have had limited access to services, but also has created significant upheaval.

People with intellectual disability continue receive all other services, including those for health and mental health, through mainstream services which are not funded or organised by the NDIS. Thus, the division between social and medical services continues to complicate access for people with intellectual disability despite broader reforms to tailor services to meet individual needs (Commonwealth of Australia, 2019). The NDIS has begun to create pathways for people with complex needs, including people with intellectual disability and co-occurring mental ill-health, by incorporating strategies such as greater inter-agency liaison and enhanced planning support (NDIS, 2019c). However, mental health services continue to lag behind in their accommodation of people with more complex or diverse needs (Evans et al., 2012; Venville et al., 2015; Govett et al., 2013).

### 1.2.3 Mental health services

It is widely recognised that services for people with intellectual disability who experience mental ill-health remain inadequate, complex and difficult to access in Australia and internationally (Venville et al., 2015; Chinn, 2016b; Trollor, 2014; Lennox et al., 2015; Whittle et al., 2018). While some specialised services are available in Australia, many people with intellectual disability access mental health services from generalist services (Weise & Trollor, 2018).



### *Disparities in health outcomes*

The shortage of appropriate services is significant, as people with intellectual disability continue to experience poorer health outcomes than the general community (Lennox et al., 2015; Howlett et al., 2015; Heslop and Glover, 2015; Trollor et al., 2017). People with intellectual disability die at a younger age when compared to their counterparts without intellectual disability. A recent NSW study found that the median age of death for people with intellectual disability was 54 years compared to 81 years in the broader population (Trollor et al., 2017). Trollor et al. (2017) found that people with intellectual disability were over-represented in numbers of potentially avoidable deaths. These disparities in health outcomes are even more apparent for the 50% of people with intellectual disability who experience mental ill-health (Govett et al., 2013; Evans et al., 2012; Tonge et al., 2013). These disparities in health outcomes are even more apparent for the 50% of people with intellectual disability who experience mental ill-health (Govett et al., 2013; Evans et al., 2012; Tonge et al., 2013). Research about service access and related health outcomes for people with intellectual disability in Australia is impeded by inconsistent data collection across health and disability agencies (Evans et al., 2012; Howlett et al. 2015).

### *Needs Overlooked*

Inconsistent data collection between agencies, and variable recognition of whether mental health users have intellectual disability in documentation is reflective of broader service inconsistencies and inadequacies (Evans et al. 2012). The mental health needs of people with intellectual disability are often overlooked or misunderstood by mainstream mental health services (Whittle et al., 2018; Venville et al., 2015).

The challenges for mental health staff to distinguish behavioural from psychiatric conditions are well documented. (Sheehan et al. , 2015; Mason & Scior, 2004). These challenges can lead to under recognition of mental health issues, and contribute to over prescription of antipsychotic medication. A longitudinal study in the United Kingdom found that prescription of antipsychotic medication was double that of the general population (Sheehan et al. 2015) . In Australia, Salomon et al (2018) reported that antipsychotics and anticonvulsants were the most frequently prescribed medication for people with intellectual disability, while ranking 36<sup>th</sup> and 37<sup>th</sup> for the general population. Such high levels of prescribing were not reflective of the actual prevalence of conditions requiring these treatments. Alarming levels of psychotropic medication use by people with intellectual disability continues to be an issue in Australia and internationally. This trend is reflective of broader questions about the preparedness of mainstream practitioners to meet the needs of people with intellectual disability (Venville et al., 2015).

Recent studies concluded that the Australian mental health workforce lacks specialised training in working with people with intellectual disability (Weise & Trollor, 2018, Weise et al. 2017). Mainstream practitioners have identified that they often feel uncertain and lack confidence when working with people with intellectual disability (Weise & Trollor ,2018). Many mental health staff lack understanding of the impact of mental health issues for people with intellectual disability (Sheehan et al., 2017; Werner 2013). Assumptions about the prevalence of mental ill-health in people with intellectual disability and shortcomings of the current healthcare system significantly impact service access (Venville et al., 2015; Lunsy et al., 2010; Bennett and Pridding, 2014; Evans et al., 2012; Cooper et al., 2007).

The failure of the mental health system to meet the needs of people with intellectual disability is reflective of broader inadequacies within the mental health system. According to the Australian Medical Association's (AMA) 2018 position statement, the mental health system in Australia lacks infrastructure and funding to provide adequate preventative and responsive services (AMA, 2018). The AMA cite Dr Sebastian Rosenberg, highlighting that in 2014-15, mental health received around 5.25 per cent of the overall health budget while representing 12 per cent of the total burden of disease. The AMA's statement is clear that people with intellectual disability who require mental health services are seeking care from a system acknowledged to be unsatisfactory for many service users. Significant reform was announced in the 5th National Mental Health Plan, 2017 to address the recognised systemic problems in the mental health sector. These reforms are discussed in more detail in the policy analysis (Chapter 4).

### *Strategies and reform*

NSW Health and the NDIS have developed targeted strategies to address the needs of people with intellectual disability who experience mental ill-health. Two key examples are the NDIS Complex Needs Pathway (NDIS, 2019c), and specialised services to support people with intellectual disability to access NSW mental health services (NSW Health, 2017).

NSW Health staff also have guidance in the 'Service Framework to Improve the Healthcare of People with Intellectual Disability' (NSW Ministry of Health, 2012). These targeted strategies are situated within a broader commitment to greater service user engagement in service provision, articulated in both the National Disability Insurance Scheme Act, 2013 and 5th National Mental Health Plan, 2017 (see Policy Analysis, Chapter 4). Personalised planning, consultation and evaluation of individual experience and agency practices are key

components in both the National Standards for Disability Services, 2013 (Department of Social Services, 2013) and National Mental Health Service Standards, 2010 (Commonwealth of Australia, 2010).

#### 1.2.4 Personalisation, planning and information access

Many of the reforms being implemented to remedy longstanding service inadequacies for people with intellectual disability pivot on greater personalisation of supports. Personalised services prioritise individual tailored service packages, driven by the needs of the individual service user (see Terms used, p. 12). The approaches to mental health service provision as well as changes seen in the NDIS are indicative of this move toward greater personalisation of services in Australia and internationally. This increasingly personalised focus seeks to replace the ‘de-individualising’ practices of the past, described in Section 1.1.1 (Wolfensberger, 1972). Personalised practices promote the realisation of the rights outlined in the UNCRPD by giving people with disability greater choice and control over the services they use.

##### *Personalisation in mental health services*

The shift to more personalised services has proved difficult in some mental health service settings. Practitioners have found personalisation especially challenging when working with people who are admitted to mental health facilities involuntarily (Waldemar et al., 2016; Maylea, 2017). Fluctuating levels of understanding and reasoning, concepts of substituted vs supported decision-making during episodes of mental ill-health, and the associated risk management are difficult for practitioners to navigate (Waldemar et al., 2016; Maylea, 2017). These difficulties are reflective of broader unease evident in the literature, as

compulsory psychiatric care is one of very few modes of healthcare which compromises the 'cherished value' of autonomy (Sjöström, 2006, p. 36). The literature highlights the difficulties associated with information access during episodes of mental ill-health and the importance of incorporating trauma-informed, recovery-oriented frameworks appropriately within involuntary psychiatric care environments (Waldemar et al., 2016).

Recovery-oriented practice and trauma-informed care are two key approaches which inform current practice, including communication between service providers and users in NSW mental health services (for definitions see Terms used, p. 12). These approaches inform the suite of mental health services offered in NSW including community support, voluntary and involuntary hospital-based inpatient services. Recovery-oriented practice encourages practitioners to focus on planning for the future and for wellness, with an emphasis on autonomy and self-agency. The principles of trauma-informed care work in parallel with recovery-oriented practice, focusing on holistic care and individual needs. The NSW Living Well Strategic Plan 2014-2024 states that trauma-informed care acknowledges the devastating impacts of past trauma and the potentially traumatising impact of mental health interventions (NSW Mental Health Commission, 2014). These two approaches outline principles to inform interaction between staff and service users, including communication strategies.

#### *Targeted strategies for people with intellectual disability*

More specific practice guidelines and related resources are also available to staff working with people with intellectual disability in mental health services. The resources include two key practice guides, *The Guide* (Department of Developmental Disability Neuropsychiatry, 2014) which provides information for mental health staff and organisations, and *The*

*Essentials* (Agency For Clinical Innovation, 2017) which has information about working with people with intellectual disability who are accessing healthcare. There are also various online resources available from the Department of Health to support health staff to meet the needs of people with intellectual disability, such as *Say Less Show More* (Agency for Clinical Innovation, 2020). These resources provide strategies to increase access and engagement of people with intellectual disability, including some guidance about communication and easy read templates.

The responsibility of agencies to offer accessible information to ensure that people with intellectual disability can engage in planning and decision-making processes is paramount. The central role of personalisation and planning processes in health and disability models underlines the importance of information access in the current service environment.

Accurate accessible information is a conduit for the right to participate in decision making, access services and engage in community life. The potential impact of individual choices on service viability in market-based systems, such as the NDIS, further reinforces the importance of information to facilitate choice. Accurate, accessible information is essential to enable service users to map out a plan which accommodates their needs, regardless of whether they require disability or health related services.

### 1.3 Accessible health information

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Healthcare systems in Australia and internationally use text documents to convey important information and this can be problematic for people with limited literacy (Papen & Walters, 2008). Many people with intellectual disability have difficulty reading and understanding information. The reliance on written communication means that people with limited

literacy, including many people with intellectual disability, have potential to miss out on opportunities to interact with essential information. The wide use of text to convey important information, including health information, underscores the value of appropriately tailored information for people with intellectual disability.

This section outlines existing knowledge about how accessible information, including easy read, is used by people with intellectual disability and concludes by introducing the integrated health literacy framework.

### 1.3.1 Accessible information for people with intellectual disability

Extensive reliance on text-based communication by essential services, such as health, can impact opportunities for people who require support to communicate to interact with necessary information. Scottish research concluded that people with communication support needs experienced negative communication within essential services, including healthcare, more often than the broader population. This study also showed that people who required communication support were often misjudged by service providers, as low literacy was often associated with limited ability to engage with information or make decisions (Law et al., 2007 in Kean, 2016). The potential for text-based information to create barriers for people engaging with information highlights the benefits of varied formats, including for people with intellectual disability.

The pervasiveness of text-based communication has been problematic for many people and various adaptations have been developed. Recognition of the barriers for people with vision impairments seeking to access text-based information precipitated the development of braille during the 1800s, for example (Jiménez et al., 2009). Similarly, in the 1960s large print books were developed for the growing number of older readers, and in 1964 Philips

developed audio-cassettes which enabled production of audio books (Tucker, 1989, p. 185). The simplification of written messages to make information easier to understand has been a more recent adaptation. The provision of information about medication, for example, has been at the forefront of the development and use of simple language and symbols to convey dosage and precautionary information for people with limited literacy (Kripalani et al., 2007).

The earliest mention of text adapted for people with intellectual disability appears to be easy read documents created in Canada in the early 1990s. Easy read documents were created by a disability agency to deliver information about several topics, including moving out of institutionalised care, and how to make a complaint (Goodwin et al., 2015). The provision of accessible information is a key resource to enable inclusion of people with intellectual disability, and this is reflected in its increased use throughout the late 1990s and 2000s (Sutherland & Isherwood, 2016; Chinn & Homeyard, 2017). A lack of accessible information for people with intellectual disability and their families has been framed as an impediment to service access. This has been recognised by policy makers as a significant issue that needs to be addressed (Commonwealth of Australia, 2009; Department of Developmental Disability Neuropsychiatry, 2014; Foundation for People with Learning Difficulties, 2014).

### 1.3.2 Easy read

#### *Defining easy read*

The term 'easy read' is used widely in the United Kingdom and by many disability services in Australia. It is not defined consistently, however, and it is used interchangeably with terms such as 'easy English', 'easy-to-read' or 'accessible information' (Kean, 2016; Mander, 2016).



A consensus is emerging that, in the context of intellectual disability, ‘accessible information’ refers to the broad suite of strategies used to enable understanding (Mander, 2016). Easy read is one strategy or option within this suite and refers to text-based information designed and constructed in a way that is easier for the recipient to understand (Hurtado et al., 2014, p. 823). In this thesis the term ‘accessible information’ denotes the broader categorisation that easy read fits within, and easy read documents are text-based documents modified for people with intellectual disability, as defined in Terms used (p. 12). Easy read documents often contain simplified text, larger font size and pictorial representations of key subjects (Sutherland & Isherwood, 2016).

Hurtado et al. (2014) state that the development of easy read requires the purposeful construction of information to convey meaning. Studies conducted into the construction of easy read documents have reached mixed conclusions about the effectiveness of document design features. The literature highlights the limited number, and inconclusive findings, of these studies and raises the issue that easy read simplification can alter intended emphasis and meaning (Buell, 2016; Bunning & Buell, 2012; Fajardo et al., 2014). Agency practices, and the varied guidelines produced to inform easy read development, reflect this lack of consistency in study findings (Fajardo et al., 2014; Sutherland & Isherwood, 2016).

Easy read is produced and used across various settings including disability service planning, inclusive research, and the collaborative development of community-based resources, for example the Oxleas ‘*can you understand it?*’ group (Rodrigues, 2014). This commitment to accessibility and collaborative resource development is also evident in practice with the array of accessible information produced in forms apart from text, such as DVD or video-based communication which continue to grow with the increasing availability of digital

technology (Boyden et al., 2009; Goodwin et al., 2015). Recent UK National Health Services guidelines and a national Scottish inclusive communication campaign are examples of policies which advocate the use of a comprehensive suite of communication options (Kean, 2016; Mander, 2016; National Health Service, 2015).

### *Easy read about health*

The research about easy read in health illustrates that there are many factors in the healthcare context and broader social environment which impact access to information.

Easy read is advocated as a tool to enable access to information, but is not an effective communication strategy for everyone with intellectual disability (Chinn, 2014; Hollins et al., 2017; Buell, 2015; Bunning & Buell, 2012; Mander, 2016; Kean, 2016; Chinn & Homeyard, 2017). The effectiveness of easy read has been shown to be impacted by numerous factors apart from design or technicalities. Factors that impact health information accessibility for people with intellectual disability mirror those identified about mental health information.

Four key areas were identified:

i) the availability of tailored communication to suit individual needs (Iacono et al., 2014; Hemsley et al., 2012; Hemsley & Balandin, 2014; Buell, 2015).

ii) the role of family and carers (Hemsley et al., 2011; Mastebroek et al., 2014a; Chinn, 2016a).

iii) the healthcare provider relationship (Mastebroek et al., 2014a; Mastebroek et al., 2016).

iv) availability of accessible community-based health promotion material (Chinn, 2014; Naaldenberg et al., 2013; Carmeli and Imam, 2014; Lennox et al., 2012).

### 1.3.3 Accessible mental health information

There is very little evidence about how accessible mental health information for people with intellectual disability is used. Some studies have been conducted about pictorial communication, group interaction and computer-based communication platforms for people with intellectual disability which included mental health related topics. Each of these areas is discussed briefly as a background to the more focused consideration of easy read in the scoping review in Chapter 2.

#### *Using pictures and images*

Several studies illustrated the benefits of using pictures or images to facilitate communication with people with intellectual disability and included some mental health scenarios or examples. Using pictorial narratives, such as wordless books, to reduce anxiety and increase health literacy have been explored in various settings, including mental health consultations (Hollins et al., 2017). Educational groups with a focus on medication information and resource testing with people with intellectual disability have also shown that symbols and pictorial representations were useful. These studies examined the effectiveness of simplified pictorial information with minimal text and are useful as context for this research. Some of these studies included medication brochures for medicines commonly prescribed to treat mental illness (Aman et al., 2007; Strydom et al., 2001).

#### *Groupwork*

Psycho-educational group programs about mental health tailored for people with intellectual disability were explored in the literature. Researchers have piloted and evaluated group mental health interventions for people with intellectual disability, with mixed results, and some of these groups reported using accessible information. However,

researchers did not describe which accessible materials were used or evaluate their effectiveness, as the focus of the research was on the group intervention (Douds et al., 2014; Sheehan et al., 2017). These studies gave a useful backdrop to the review of easy read mental health information but were not included in the scoping review due to the absence of detail about the accessible information used.

### *Electronic or computer based strategies*

In addition to face-to-face opportunities for information exchange, in recent years there has been greater emphasis on computer-based or e-health strategies in mental health service provision. E-health initiatives have had limited focus on accessible information for people with intellectual disability. It is clear from the literature that there is still more to learn about how internet-based mental health service programs and community mental health messages can meet the communication needs of people with intellectual disability (Kirk et al., 2014; Sheehan & Hassiotis, 2017). There could be opportunities to use simplified text such as easy read in an online format, and the use of remote technologies such as e-health for people with intellectual disability was an area identified for further exploration (Sheehan & Hassiotis, 2017).

The lack of accessible mental health information available to people with intellectual disability, despite calls for increased use of strategies such as easy read to ameliorate the disparities described in Section 1.2 raises many questions. It is evident that people unable to use standard text documents experience disadvantage in many areas, including health (Papen & Walters, 2008). However, the relationship between accessible information, easy read and mental health outcomes for people with intellectual disability is unclear and

worthy of further exploration. The concepts developed in health literacy studies offer a useful scaffold for this exploration.

#### 1.3.4 Health literacy

##### *Defining health literacy*

The concepts found in the field of health literacy offer a framework to better understand the relationship between easy read, accessible information and broader complexities that impact health service access and outcomes. According to Sørensen et al. (2012), health literacy is:

linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Sørensen et al., 2012, p. 3).

This understanding of health literacy offers a relevant framework for this research. It presents a scaffold on which to consider the rights articulated in the UNCRPD within the health context. The factors impacting information accessibility for people with intellectual disability about mental health relate to a broad array of factors. Health literacy is a useful framework to explore these factors, although health literacy research has rarely included people with intellectual disability (Chinn, 2011).

Sørensen et al.'s (2012) definition of health literacy captures the move away from functional literacy to incorporate broader aspects of health literacy. The realisation that people with low literacy had markedly poorer health outcomes than those of the broader community

fuelled increased interest in health literacy research and since around 2000 there has been exponential growth in this field (Marks et al., 2008; Nutbeam, 2000; Nutbeam, 2008; Sørensen et al., 2012). Researchers and practitioners recognised that the reliance of modern cultures on text for knowledge transfer led to a gap in health outcomes directly related to functional literacy (Marks et al., 2008).

### *Agency practices*

Some scholars questioned the traditional focus on individual skills and highlighted the influence of agency practices which were often difficult to navigate (Raynor, 2012). Often groups who were not literate or who found services difficult to access were already marginalised by conditions or circumstances. These included environmental factors such as migration, poverty or lack of access to education or more intrinsic factors such as illness. Nutbeam's work (2000, 2008) was a foundation for a broadening of the concept of health literacy from static individual skills linked to functional literacy, to interactions situated in a network of influences and broader health determinants (Nutbeam, 2000; Nutbeam, 2008; Chinn, 2011).

The focus of this research into information about mental health also relates to the more specific field of mental health literacy. The domain of mental health literacy has grown in parallel to that of the broader health literacy field. The specific focus of mental health literacy underpins the community mental health promotion campaigns in the Australian context (Jorm, 2012; Jorm, 2015b; Jorm, 2015a). The breadth of the framework devised by Sørensen et al. (2012) incorporates the distinctive issues about information access identified in mental health literacy studies alongside those associated with intellectual disability.

## Multiple factors impact health outcomes

The framework devised in Sørensen et al.'s 2012 systematic review of health literacy literature encompasses a model which reflects the interplay of factors impacting health literacy and ultimately health outcomes. A multiplicity of interrelated factors can impact access to health and health information for people with intellectual disability (Emerson & Hatton, 2007). The framework enables incorporation of systemic socio-economic inequalities, policy and agency practices alongside factors impacting individual communication. Sørensen et al.'s (2012) model enables a greater understanding of how easy read information about mental health for people with intellectual disability relates to information accessibility and to health outcomes more broadly.

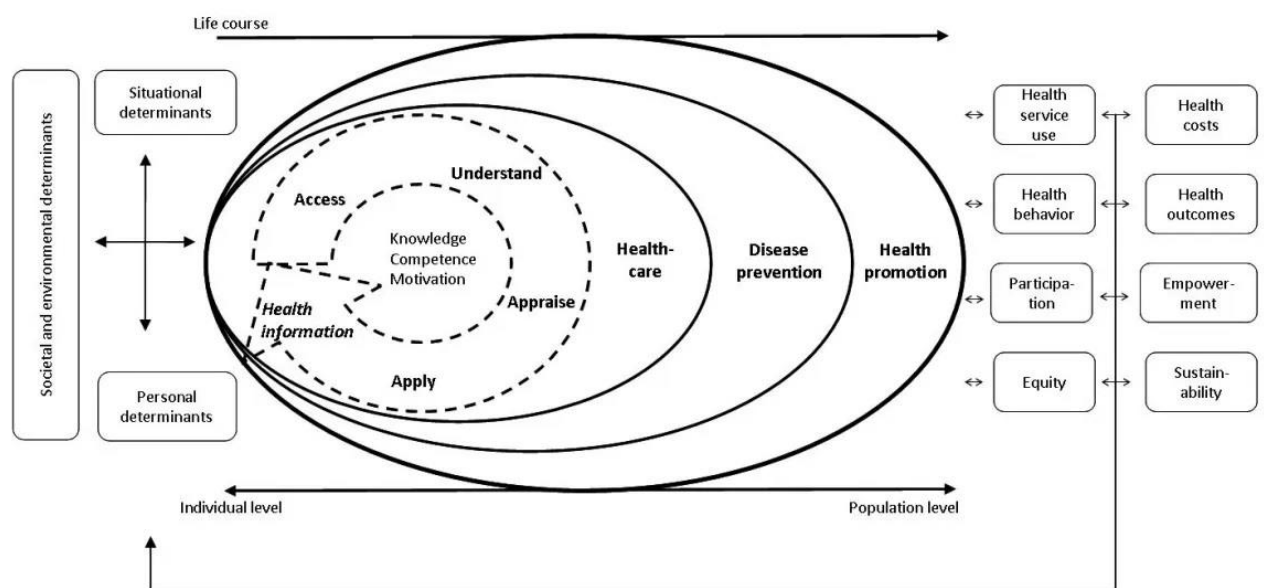


Figure 1 Integrated health literacy framework

Figure 1 shows Sørensen et al.'s integrated health literacy framework (Sørensen et al., 2012, p. 9). The comprehensive nature of Sørensen et al.'s (2012) model contextualises health

information exchange for people with intellectual disability about mental health, incorporating the domains of healthcare, disease prevention and health promotion. The integrated health literacy framework illustrates the link between easy read, accessible information and health outcomes. The model has capacity to understand the roles of individual need, family or carer, health practitioner relationships and of agency practices in communication.

The focus of the research undertaken for this thesis is on the concepts of accessing, understanding, appraising and applying information and the impact of 'social and environmental determinants' on this process. These concepts are situated at the left end of the model (Figure 1). The process of increasing health literacy moves from information access, defined as the ability to 'seek, find and obtain' information, to understanding or comprehending information, to then be able to appraise or 'interpret, filter, judge' the information and finally to the endpoint of applying or using the information that was accessed, understood and appraised (Sørensen et al., 2012, p. 9).

#### 1.3.5 Integrated health literacy framework and intellectual disability

There are many concepts in the integrated health literacy framework that marry well with disability studies as a scaffold for this research . Immediately apparent is the interplay between individual characteristics and environment explored in critical disability studies (Shakespeare, 2014). This interplay is explicit in Sørensen et al.'s (2012) work, in the impact of agency accessibility or 'system readability' on the level of individual resources or the 'competency' required to interact with health information. The interplay between individual 'competencies' and agency 'readability' as articulated by Sørensen et al. is a useful starting point for exploring accessible information (Sørensen et al., 2012, p. 10). This interplay



between individual and environmental factors highlights the suitability of the integrated health literacy framework, and also illuminates some divergence between Sorensen et al.'s model and disability studies.

The term 'competency' as used by Sørensen et al. (2012) requires some clarification.

Sorensen et al. use the term competency in relation to the activities of accessing, understanding, appraising and applying information and this conveys a sense of individual mastery. Sørensen et al. (2012) note that the family or carer facilitate much of the daily care and decision making related to chronic illness, and this is a recognition also relevant for people with intellectual disability (Sørensen et al., 2012, p. 8). In this research, the term 'competency' is used acknowledging that many people rely on others to enable the development and use of the 'competencies' required to access health information and care. The cultural values surrounding dependence and autonomy found in ethics of care literature (Morris, 2001; Winance, 2016) are useful when considering the objectives to access, understand, appraise and apply information. The understanding that relationships of support are integral to the competency to interact with health information is a foundation of this research.

Considering relationships of support as an integral element for health literacy is reflective of recent scholarship about intellectual disability and health literacy. Chinn (2017) argues that concepts such as critical and communicative health literacy enable greater understanding of how people with intellectual disability engage with health information. Communicative health literacy incorporates interaction to gain information and critical health literacy relates to the skills required to consider and analyse or appraise information (Nutbeam

2000). An array of factors impact opportunities to interact critically with health information including knowledge of the health system, emotional responses and relationships of support (Chinn 2017, p. 346). This research is underpinned by an understanding that many people, including people with intellectual disability, value and require support to engage with health information.

Relationships of support are represented on the left end of Sørensen et al.'s (2012) model, within the sphere of 'societal and environmental determinants' which includes 'personal' and 'situational' determinants (Figure 1). The interdependence in relationships of support explored in this research does not seem to be reflected in these categories or in the definition as determinants. Due to the importance of relationships of support in this research the social and environmental determinants have been reframed as 'social and environmental influences' to accommodate these elements in the analysis.

#### *The obligation to provide health information.*

A final comment about using the integrated health literacy framework relates to the concept of 'agency readability'. The obligation of health agencies to make accessible information available is a foundation of this research and the concept of agency readability described above is therefore central. 'Readability' refers to the level of agency complexity for service users navigating the service and this includes the availability of accessible information. The role of agencies to provide information traverses Figure 1 and is relevant to all types of health information services made available, ie. healthcare, disease prevention and health promotion. To avoid confusion, as this research focuses on easy read, the term 'agency accessibility' is used when referring to agency systems or processes, rather than 'readability'.

The integrated health literacy framework delivers a means to explore the connection between agency accessibility, easy read, health information and outcomes. Many people with intellectual disability and advocates have suggested that increased availability of easy read information could make information more accessible, enable greater engagement in decision making and ultimately improve health outcomes. The integrated health literacy framework scaffolds evidence about the connection between using easy read and health outcomes. The next step in exploring this gap in knowledge is to further articulate what is already understood about using easy read mental health information. The next chapter uses the concepts found in health literacy to document what is known about using easy read mental health information, and articulate what the literature says about making mental health information accessible for people with intellectual disability.

## CHAPTER 2: SCOPING ACCESSIBLE MENTAL HEALTH INFORMATION

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This chapter focuses on the literature about accessible mental health information for people with intellectual disability and presents findings of a scoping review on this topic. The purpose of this chapter is to explore recent literature about accessible mental health information in order to delineate gaps in knowledge and define the scope of this research. People with intellectual disability have had little presence in the mental health literacy or health literacy spheres, as discussed in Chapter 1. The small number of studies in the literature which focus on mental health information for people with intellectual disability is reflective of this broader lack of representation.

This chapter includes the scoping review methods, findings and an exploration of their relationship to the broader scholarship about easy read and accessible health information. Research questions developed from the findings of the scoping review are presented at the conclusion of the review.

### 2.1 Scoping review method

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A scoping review was the selected approach as it enabled a variety of study designs to be included. Whilst rigorous, a scoping review is an iterative approach, flexible enough to

enable repetition of search steps to include alternate search terms if required (Arksey & O'Malley, 2005; The Joanna Briggs Institute, 2015). The framework for review, as outlined by Arksey and O'Malley, had five key stages: identifying the research question, identifying relevant studies, study selection, charting the data, collating, summarising and reporting results.

*Identifying the research question:* The background information presented in Chapter 1 informed the research question developed to frame this review. The scoping review was guided by the question: *How is easy read used to make information more accessible for people with intellectual disability about mental health?*

*Identifying relevant studies* The wide-ranging spheres of learning canvassed in Chapter 1 revealed a gap in knowledge, indicating that a broad search approach would be most likely to capture relevant studies. Databases were selected to encompass the breadth of the subject area as the review potentially spanned the disciplines of mental health, disability, communication and social justice. The databases searched were EMBASE, PROQUEST, SCOPUS, Web of Science and OVID Psych.

*Study Selection* Articles were included for review if they had been published in English in a peer reviewed journal between 2006 and 2018 and focused on accessible information about mental health for people with intellectual disability. To be included articles were required to have the three elements of intellectual disability, mental health and accessible communication as the primary focus. The accessible information included could be about mental health conditions, services or any aspect of mental health care. The quality of accessible information or development techniques were not considered. All study designs, commentary or opinion pieces were included. Electronic media, computer-based

communication, group-based interventions and clinical assessments were excluded. These criteria were devised to incorporate research related to using easy read or similar accessible material devised for people with intellectual disability in a mental health setting.

The databases selected required an array of terminology to be used when searching, in order to capture relevant studies. A range of key words, listed in Table 1, were identified from the literature and piloted in consultation with scholars from medicine and social policy faculties, practitioners, and university library staff.

**Table 1: Scoping review key search terms**

<b>Key word</b>	<b>Synonyms</b>
<b>Accessible information</b>	Easy-read, plain English, easy-to-read, adapted language, information literacy, self-management, communication, assistive technology
<b>Mental health</b>	Psychological, emotional well-being or health, psychiatric, mental illness
<b>Intellectual disability</b>	Cognitive disability, mental disability, special needs, developmental delay, developmental disorders, mental retardation, learning difficulties, cognitive disab*

A total of 1795 articles were identified using the search strategy outlined, finding 869 unique articles. The 869 articles were assessed by title and 190 were potentially covering accessible information about mental health for people with intellectual disability. After abstracts were reviewed, 85 articles were considered and a detailed review of the content revealed that five had a focus on accessible text-based information for people with an intellectual disability about mental health. References of these articles were cross- checked for other relevant studies, and this process identified no further articles fulfilling the criteria. The number of relevant articles was limited. If languages other than English had been

included in this review, more relevant studies might have been found. Similarly, if grey literature included in this scoping review more relevant information may have been gleaned.

*Charting the data* the following information was charted and summarised; authors, participants, study aim, study design, quality and key results.

As this was a scoping review article quality and study design were acknowledged but did not preclude inclusion in the review. The articles located were of varying quality. The hierarchy of evidence-for-practice in qualitative research developed by Daly et al. (2007) describes four levels of evidence. Level 1 are generalisable studies, level 2 conceptual, level 3 descriptive and level 4, single case studies. Four of the included articles were conceptual or descriptive studies, implying that the evidence was reliable. One article was a commentary piece, so caution applying the evidence is noted in the analysis. These categorisations have been noted in table 2.

*Collating, summarising and reporting results:* The integrated health literacy framework was used to guide the analysis of findings. The integrated health literacy framework (Sørensen et al., 2012) is a suitable framework to analyse the many factors that affect the accessibility of mental health information for people with intellectual disability, as outlined in Chapter 1. Sørensen et al.'s (2012) concepts of accessing, understanding, appraising and applying health information were used as a framework to examine the available literature to learn how easy read information about mental health is used to make information more accessible for people with intellectual disability.

The concepts of 'accessing, understanding, appraising and applying' information about health were explored in relation to accessible information about mental health in the

selected articles. Sørensen et al.'s health literacy model focuses on the ability to 'access, understand, appraise, and apply health information' to enable decisions about health, as presented in Chapter 1 (Sørensen et al., 2012, p. 3). The process of increasing health literacy includes information access, defined as the ability to 'seek, find and obtain' information; to understanding or comprehending information; to then appraise or 'interpret, filter, judge' the information and finally to the endpoint of applying or using the information that was accessed, understood and appraised (Sørensen et al., 2012, p. 9).

## 2.2 Scoping review results

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The five articles identified in the scoping review are described in Table 2. Two of the articles were explicitly about the use of easy read for people with intellectual disability about mental health, two other studies related to mental health information accessibility more broadly and one was a guide for psychiatrists about communicating with people with intellectual disability. The studies all included people with intellectual disability. The research conducted by Dunn et al. (2006) and Ferguson and Murphy (2014) both included only participants with intellectual disability. Hemmings et al. (2013) included service users and carers. Whereas Gratsa et al. (2007) included carers and paid workers, as well as people with intellectual disability. All the articles incorporated the three elements of intellectual disability, mental health and accessible communication as the primary focus. Studies did not indicate participants' level of intellectual disability. Detail about IQ or level of disability was not ascertained. This information was not pursued as it was not considered essential due to the nature of the review and scope of the inquiry.



The included articles emphasised the integral role of families and carers in finding and using health information. The articles reviewed mention the difficulties faced by people with intellectual disability who are reliant on support workers or other staff to facilitate health information, but this issue is not discussed in detail. The content of this chapter is reflective of findings from the included studies. The implications of health service reliance on family support and associated complexities was raised by participants of this research. These complexities are presented in Chapters 5-7 and discussed further in Chapter 8.

**Table 2: Accessible information about mental health for people with intellectual disability: summary of papers reviewed**

<b>Authors</b>	<b>Participants</b>	<b>Study Aims</b>	<b>Study design</b>	<b>Quality *</b>	<b>Key Results</b>
Boardman, Bernal and Hollins, 2014  NHS Foundation Trust UK	no study results	Guide only	Guide for psychiatry practice when working with people with intellectual disability	commentary	Guide for practitioners reinforcing the value of accessible information.
Dunn et al., 2006  West Midlands, UK	<i>n= 19 participants</i>	To examine impact of accessible information for people with mild or moderate learning disability (video) to increase knowledge about psychology services	Pre, mid-point and post testing – 10 question comprehension test	Level 2	Participants’ knowledge increased significantly after watching the video. Participants were better able to answer questions when the video was presented in short sections rather than uninterrupted.
Ferguson and Murphy, 2014  University of Lancaster, Lancaster, UK	<i>n= 28</i>	To investigate the capacity of individuals with intellectual disabilities to make decisions about their medications, and evaluate the impact of training (information) sessions.	3 training sessions about medication use and consent  pre – post testing	Level 2	Confirmed the value of accessible information and the opportunity for clarification to increase knowledge and capacity to make decisions about medication.
Gratsa et al., 2007  King’s College London, UK	<i>n= 17 Carers</i>  <i>n=8 Service users</i>  <i>n=7 Paid care-workers</i>	To develop a guide for families of people with intellectual disability who experience mental ill-health	Semi-structured interviews  Focus groups  Structured questionnaire	Level 3	Families or carers identified the need for an accessible, understandable guide and were satisfied with the guide.  The involvement of stakeholders was recognised as a key element to ensure relevance.  The small study size was identified as a limitation.

Hemmings et al., 2013	<i>n=20 Service users</i>	To develop and evaluate the use of portable accessible information for use during mental health crisis	Qualitative interview Case study	Level 3	The information wallets were used to convey information in various settings and increased confidence to convey information.  No mental health crises occurred during the study and the use of the crisis wallets could not be evaluated for this purpose.
NHS Foundation Trust, London, UK	<i>n =17 Carers</i>				

*\*NOTE Quality of evidence: Level 1 are generalisable studies, level 2 conceptual, level 3 descriptive and level 4, single case studies (Daly et al. 2007).*

### 2.2.1 Accessing information

Accessing information is presented as the first element in Sørensen et al.'s (2012) integrated health literacy framework. The articles claimed that access to health information was a right which underpinned health service practice. The importance of timely access to information and the role of the family or carer in enabling access were recurrent themes. All the authors argued that access to information was a right not always experienced by people with intellectual disability. Dunn, Kroese, Thomas, McGarry & Drew (2006, p. 34) and Ferguson and Murphy (2014, p. 865) presented an ethical imperative for access to information and cited inequalities relating to information access and informed consent as a motivation for inquiry. Similarly, Gratsa et al. (2007, p. 77) stated that the guide was produced in response to an identified lack of information, linking this to broader health inequalities. Boardman, Bernal & Hollin's (2014, p. 35) practitioner guide highlighted the ethical responsibility of service providers to adjust communication material to enable information access.

Two themes relevant to the dimension of access to information were the importance of timely access and the role of families and carers in the process of accessing information. These two aspects of access were evident in the project design and findings of both Hemmings et al. (2013) and Gratsa et al.'s (2007) work. An aim of the accessible information wallets in Hemmings et al.'s (2013) study was to provide information at a time of crisis to minimise the stress of the person with disability and their families or carers. Carers were given the option to attend a meeting to develop the crisis wallet. Most of the participants (17/20) chose to do so, evidencing the significance of their carer relationship to support access to information. The authors were not able to measure the effectiveness of the

information wallet to meet its intended goal as no crises were experienced during the trial period. However, the wallet gave participants access to information for other purposes. Similarly, in Gratsa et al.'s (2007) work, the guide targeted family and carers as a conduit for information and reinforced their role in enabling timely information and service access. Gratsa et al. (2007) used inclusive methodology to develop a guide to support families/carers which enabled access to both information and services. The authors noted the limitations of a small study size for generalising findings or confirming the value of the guide for the target population. The guide was evaluated by carers, who reported that, although more detail would have been beneficial, it was useful and easy to understand, reinforcing their role in enabling information access (Gratsa et al., 2007).

#### 2.2.2 Understanding information

The second element outlined by Sørensen et al. (2012) is understanding information. The articles explored how to support and facilitate understanding of health-related information. The studies reviewed highlighted the following themes: the role of family or carer to facilitate understanding, the need to consider fluctuations in comprehension, the value of varied information formats, and the opportunity for interaction.

The integral role of the family or carer to support the person with intellectual disability to gain understanding was evident in all the articles, especially Gratsa et al. (2007) and Boardman et al.'s (2014) work. The claim that the family or carer were well positioned to support a person with intellectual disability to understand tailored information underpinned Gratsa et al.'s (2007) inclusive methodology and was confirmed in the paper's findings. Similarly, Boardman et al.'s (2014) guide highlighted the role of the family to facilitate

understanding, particularly when people with intellectual disability have specific communication needs about their mental health.

The episodic nature of some mental health conditions and the potential impact of this on the ability to understand health information was evident in Ferguson and Murphy's article (2014, pp. 137-138). Ferguson and Murphy's (2014) study set out to determine capacity to consent via standardised testing and to then examine the impact of training on capacity.

The authors did not examine the provision of 'take home' information, inclusion of family or carer or the long-term impact of the training. The findings confirmed both the importance of considering individual circumstances which may affect understanding or capacity at a particular time, and the value of tailored interactive information exchange.

Flexibility in information format and the importance of interaction and collaboration to facilitate understanding was reinforced in each of the five articles. Hemmings et al.'s (2013) study examined the collaborative development of a text-based document to provide required information in a portable format, which proved to contribute to understanding.

Ferguson and Murphy (2014) used interactive training sessions to increase understanding, and Dunn et al. (2006) reported increased understanding when testing comprehension after people with intellectual disability viewed small chunks of information via video. Boardman et al.'s (2014) work highlighted the reciprocal nature of understanding – as the practitioner learned about the service user and modified information accordingly, the service user could understand more about their health needs.

The work of Boardman et al. (2014) described varied communication tools and advocated the use of easy read information as a script for verbal explanations and to guide discussions.

The consideration of findings from the studies, along with Boardman et al.'s (2014) guide

reinforced the value of varied information formats and flexible communication strategies developed in collaboration with the person accessing the health information to ensure understanding.

### 2.2.3 Appraising information

Appraisal is the third element of the integrated health literacy framework. The importance of appraising information was most evident in Ferguson and Murphy's (2014), and Dunn et al.'s (2006) studies as these examined the concepts of choice and consent. The role of the family to support appraisal was also evident.

Ferguson and Murphy (2014, p. 871) argued that historically, people with intellectual disability have been denied the right to appraise information to make decisions about healthcare and are often only provided with limited options to consider. Their study found that interactive information sessions enabled understanding to facilitate appraisal. They contrasted interactive information with the provision of a modified leaflet which had proven ineffective in Strydom and Hall's earlier research (Ferguson & Murphy, 2014; Strydom et al., 2001). Ferguson and Murphy's (2014) work found the use of simple messages to be effective in the training provided. The article did not detail the method of training delivery, so it remains unclear whether easy read material was used, or the effectiveness of easy read in this context. However, Ferguson and Murphy's (2014) findings emphasised the importance of interaction when compared to the provision of static information when communicating with people with intellectual disability to facilitate appraisal of information.

Another aspect of information appraisal was the evidence that many people with intellectual disability relied on family or a carer to appraise information with them or on their behalf. This informal support for appraisal was seen most clearly in the development

and evaluation of the guide in Gratsa et al.'s study (2007). Boardman et al. (2014) similarly presented that clinicians have the 'ethical responsibility' to adapt communication. The scenarios presented in the article indicate that this included adaption of information, involvement of family or carer and the opportunity for verbal exchange to enable appraisal (Boardman et al., 2014).

#### 2.2.4 Applying information

The final element presented by Sørensen et al. (2012) in the integrated health literacy framework is applying information. The short-term application of information was explored in all of the articles included in the review, but not the long-term. Four themes were evident in the articles about the applying information dimension of health literacy. These themes were about consent, family or carer capacity, confidence, and the impact of the service provider relationship on the readiness to apply information.

Both Ferguson and Murphy's (2014) and Dunn et al.'s (2006) studies explored the effectiveness of accessible information to enable people with intellectual disability to make choices. Consenting to treatment in Dunn et al.'s (2006) study, or a decision about medication in Ferguson and Murphy's (2014) study, was an expression of the ability to 'apply' information. Both studies highlighted the benefits of accessible information but neither used easy read as a stand-alone tool. Dunn et al.'s (2006) study emphasised the advantages of video communication, whilst Ferguson and Murphy's (2014) study compared interactive learning to Strydom's earlier work with static information. Ferguson and Murphy's (2014) work highlighted the limitations of only using an easy read brochure to enable people to appraise and apply information and accentuated the benefits of opportunities to ask questions and interact with information.



The role of the family or carer to enable the person with intellectual disability to apply information was not directly explored by any of the studies reviewed but remained an underlying theme. It was implied in the work of Boardman et al. (2014) in the practical strategies provided to practitioners and was central to the purpose of the guide designed and produced in Grasta et al.'s work. Ferguson and Murphy (2014, p. 872) did not directly address the role of the family or carer, but they concluded that training for carers is important because of their role in monitoring and supporting medication-related information to be applied.

In Hemming et al.'s (2013) study, the intended opportunity to apply the information in the crisis cards did not eventuate, however, the utility of the cards was demonstrated by people using the information in other settings which evidenced the skill to apply. The role of easy read in this process was not explicit, but conveying information via the tailored information in the crisis wallet resulted in participants reporting increased confidence to better communicate their needs and access appropriate services.

The capacity of people with intellectual disability to apply information was also influenced by the health provider relationship. Ferguson and Murphy (2014) found that whilst people understood the information about medication, they were at times reluctant to contradict GPs' opinions due to a 'very clear power differential' (Ferguson & Murphy, 2014, p. 871). Similarly, Dunn et al. (2006) found that even though participants gained greater understanding and appraised the information presented, they were sometimes reluctant to express their opinion for fear of contradicting that of the healthcare provider. These studies demonstrated that the service provider relationship had great potential to impact the service user's capacity to 'apply' knowledge even when they gained understanding from the information. The studies showed that although accessible information, such as easy read,

can enable understanding, this did not always translate to application in the form of health-related decisions or consideration of options.

## 2.3 Making mental health information accessible

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This scoping review reinforced that the process of accessing, understanding, appraising and applying health information was not reliant upon static capabilities, but dependent on factors beyond individual skill or circumstance. The scoping review confirmed that there was a shortage of evidence about the ways that easy read material is used in mental health communication. The findings mirrored those of broader studies about accessible health information for people with intellectual disability in other settings as discussed in Section 1.3. Findings from the five articles included in the scoping review have been integrated with the background literature presented in Chapter 1 to present a summary of what is known about using easy read about mental health. The term ‘broader literature’ is used to describe the sources outside of the scoping review.

There were four factors that influenced access to information: collaboration and flexibility to meet individual needs, the service provider context, the role of the family or carer, and service system complexity. Each of these factors is discussed to inform what was known to date about the question, *‘How is easy read used to make information about mental health more accessible for people with intellectual disability?’*

### 2.3.1 Collaboration and flexibility

In the articles reviewed, easy read was one option in a suite of accessible information formats and there was an emphasis on collaboration between the parties seeking to

communicate to establish effective communication channels. These findings reflected the broader literature about easy read which revealed an emerging acknowledgement of the importance of varied communication tools adapted to suit personal need (Mander, 2016; Buell, 2015). The studies included in this review revealed two key principles that are relevant for the use of easy read about mental health.

The first principle was that easy read was one option of many to enable access. Strategies that did not rely on text-based communication were more accessible in some settings, as seen in Dunn et al.'s (2006) study. Increased availability of technology brings many innovative options such as video and tablet applications that can be used/adapted to best suit individual need which would benefit from further exploration (Borg et al., 2015).

Similarly, other studies applied tools such as wordless picture narratives to facilitate interaction and to reduce the complexity of documents, with the purpose of avoiding any anxiety that some people feel when presented with text (Hollins et al., 2017).

The broader literature highlighted the benefit of a choice of communication options within health services (Kean, 2016). Tailoring information to meet individual needs has been shown to be essential to enable access, as discussed in Chapter 1. The increased use of personalised service delivery models in the disability sector is an example of an area which has embraced the need for individual choice and variety of communication strategies. The recognition of individual needs has led to the development of numerous tools to enable tailored planning, decision making and consent. These documents are developed collaboratively and offer flexibility in design and medium with the option of a mix of visual representation and simplified text to fit individual communication preference, for example the one page profile (Sanderson, 2014).

The second principle related to flexibility and collaboration was that accessible information was most effective when there was opportunity for interaction. Ferguson and Murphy's (2014) study highlighted the benefit of the opportunity to ask questions. The value of providing an opportunity to consider and ask questions when compared to the provision of a static text document was clear in Ferguson and Murphy's (2014) findings. Similarly, the use of accessible documents to directly facilitate communication and interaction in a time of need was evident in Hemming's study. In Boardman et al.'s (2014) guide, easy read was presented as an option to facilitate understanding between service providers and people with intellectual disability. Easy read was also useful as a guide for conversation for family or carers to use at an appropriate time. The scoping review findings reflect wider evidence about using easy read as a facilitator of communication rather than a stand-alone tool (Mander, 2015).

Working collaboratively to tailor communication to meet individual needs was shown to be beneficial for people with intellectual disability and people who experience episodes of mental ill-health. It is recognised in the broader literature that people with intellectual disability have varied skills which can be underestimated or overlooked if a tailored, interactive approach is not taken (Buell, 2015). This is particularly so for people with complex communication needs who rely on unique communication techniques or technologies (Hemsley & Balandin, 2014). People with intellectual disability may require support to process and understand information, not just to read text or overcome literacy issues. Similarly, for people experiencing mental ill-health, consideration may need to be given to the way in which an individual's mental health condition impacts communication. This includes both direct impact of the condition as well as the potential impact of stigma associated with their condition on their willingness to engage with information (Jorm, 2012;

Wei et al., 2015). Whether easy read or an alternate tool, the opportunity to interact, ask questions and evaluate options were shown to be of great benefit in ensuring effective communication (Chinn, 2016a).

Facilitated groups also provided opportunities for interactive communication. Facilitated groups are used in mental health services for both educational and therapeutic purposes and can include accessible tools such as easy read. Group programs have potential as an avenue for psycho-education with the use of accessible information and opportunity to interact with information as described in Ferguson and Murphy's study (2014). A small number of studies have evaluated the effectiveness of groups targeted to people with intellectual disability and a number reported that accessible information was used. As discussed in Section 1.3.3, it is difficult to ascertain the value of accessible information in the group context as many other factors influenced the outcomes measured (Douds et al., 2014; Kirk et al., 2014; Sheehan et al., 2017). Adaptation of therapeutic and educational group material to suit the needs of people with intellectual disability has been identified as an area which would benefit from further exploration (Kirk et al., 2014).

### 2.3.2 Service provider context

The literature included in this scoping review highlighted that a common context for information exchange about mental health is in consultation with a healthcare provider. The broader literature demonstrates that healthcare providers play a vital role in communicating health related information to people with intellectual disability and their families (Mastebroek et al., 2016; Taggart et al., 2011; Taua et al., 2012). The studies in this review confirmed the broader literature and highlighted the influence of both the practitioner's skills and their awareness of the influence of the service provider relationship.

The studies in this scoping review and the broader literature indicated that practitioners benefited from an awareness of varied forms of communication. Having this knowledge enabled practitioners to facilitate flexible, collaborative information exchange with the person with intellectual disability and their family or carer (Boardman et al., 2014; Kean, 2016; Mander, 2015). However, both service providers and service users have identified communication as an area of concern (Robinson et al., 2016). It is recognised that when working with people with intellectual disability there is a lack of shared vocabulary around emotional and mental health and a reluctance to discuss these issues (Chinn, 2016a).

Practitioners' limited knowledge of communication strategies is indicative of a broader lack of confidence to work with people with intellectual disability. In a clinical setting, mental health issues can be 'overshadowed' by issues associated with intellectual disability which impacts treatment and has implications for effective communication (Mason & Scior, 2004). Studies have revealed that health practitioners often feel ill-equipped to work with people with intellectual disability, citing communication as a particular issue and asserting the value of targeted training (Wullink et al., 2009; Mastebroek et al., 2014b; Werner et al., 2013).

In addition to practical knowledge and skill, an awareness of the impact that the health service context can have on effective communication is beneficial, particularly the potential impact of the service provider relationship. The relationship between service user and healthcare provider was shown to have potential to enhance or hinder the service user's opportunity to access, understand, appraise and apply health information (Mastebroek et al., 2016; Chinn, 2016a; Chinn, 2019b). The context of information exchange has been shown to significantly impact effectiveness of communication.

The power disparities between healthcare provider and service user have great potential to impact the effectiveness of information exchanged about mental health. Such disparities were evident in the literature about mental health included in the scoping review and reflected publications about accessible information about health more broadly (e.g. Law et al., 2005; Chinn, 2016a; Chinn 2019b). The tendency of people with intellectual disability to acquiesce in such relationships can amplify these underlying disparities, which may impact the ability to 'appraise' and limit the choices considered to 'apply' information (Mander, 2016; Sigelman et al., 1981). It has been observed that efforts by health services and practitioners to simplify information can unintentionally reinforce underlying power imbalances between service provider and user (Buell, 2016; Chinn & Homeyard, 2017).

Practitioners' awareness of these underlying disparities was identified as one way of reducing the impact of this imbalance on communication. Practitioner attitude and training in relevant skills may address this disparity in part, but the health literacy literature reveals that increased knowledge and confidence of people with intellectual disability accessing services was also beneficial (Fergusson and Murphy, 2014; Chinn, 2016a, 2017).

### 2.3.3 Role of family and carers

The articles reviewed reinforced the benefit of accessible information such as easy read to assist families and carers to support engagement with information and services. In communication exchange with health providers, families or carers often supported access, understanding, facilitated appraisal and enabled the person with disability to apply the knowledge when appropriate (Gratsa et al., 2007; Brolan et al., 2012). Boardman et al. (2014) acknowledged the use of easy read to enable families to convey information to their family member with intellectual disability both during and after health appointments.

Hemmings et al.'s (2013) work also reinforced the value of accessible information when communicating medical information at a time of need. For people with intellectual disability, easy read can be one strategy to enable family members to support access to information.

Families or carers play an integral role in advocacy and decision making for people with intellectual disability (Brolan et al., 2012; Werner, 2013) and the importance of healthcare providers maintaining communication with family or carer is well documented (Kroese et al., 2013; Mastebroek et al., 2016; James, 2016). People with more significant intellectual disability and/or communication limitations often require greater support from family or carer to gain access to information and enable choice making (Werner, 2013). Additionally, for people who experience episodic mental ill-health, the family or carer have a valuable role in the recognition of ill-health and provision of timely information and support (Jorm, 2012; Wei et al., 2015).

For many people with intellectual disability, support from family/familiar carers is essential in making information accessible. Family or carers can offer support in bridging gaps in gathering, understanding and remembering information as they hold a unique position in the life of the person with intellectual disability. However, carer relationships has also been shown to bring complexity to communication and decision making, as carers/families can be both supportive and at times overprotective or limit options for a person with intellectual disability (James, 2013; Kroese et al., 2013).

The family or carer's role in identifying issues and giving timely support to apply knowledge or access appropriate services can have significance for people who experience episodic mental health issues (Wei et al., 2015; Jorm, 2015a). Whilst the role that family or carers



play to enable access to services and supports is recognised in the literature, it is also evident that not all people with disability have access to the same quality of support from family or paid carers. A lack of carer knowledge about relevant medical information is highlighted as an issue by Dunn et al. (2006) and the guide produced by Gratsa et al. (2007) was directly seeking to address this.

The provision of accessible information, such as easy read, not only has potential to increase the opportunity for independent access to information for people with intellectual disability but also to provide more understandable information for families and carers. The provision of easy read could benefit families or carers with less knowledge or capacity to offer support to a person with intellectual disability accessing health information, however, the use of easy read in this way remains unexplored.

#### 2.3.4 Service complexity and information availability

Sørensen et al. (2012) argue that implementing strategies to simplify service access decreased the reliance on individual or family or carer skill and placed responsibility upon the service provider to deliver services in an accessible way. Providing health information is a key role of health agencies and organisational structures need to support people to find the information they need. For people with intellectual disability and mental ill-health the broader systemic issues are well documented, and these issues create a problematic backdrop to health information access.

The discussion above regarding the role of family support in service access highlights this issue, for while accessible information about health and health organisations could increase the ability of people with intellectual disability and their families to access services, an underlying systemic complexity remains. The conundrum emerges that whilst accessible

information is considered a strategy to improve service access, service agencies often provide this information and yet systemic barriers impede access to these agencies (Gratsa et al., 2007; Venville et al., 2015). The service system's broader structures create the context for information exchange and have potential to impact its availability and effectiveness. Health information is a central tenet in Sørensen et al.'s (2012) model and a key element in increasing health literacy and outcomes.

The provision of accessible community-based health promotion information has been identified as one strategy which could be explored to increase the capacity of people with intellectual disability to access health services (Carmeli & Imam, 2014; Chinn, 2014). There have been a limited number of targeted mental health resources developed for people with intellectual disability. For example, *Feeling Down* produced by the Foundation for People with Learning Disabilities in the UK (Foundation for People with Learning Difficulties, 2014). In Australia, some resources are available from disability agencies, such as SCOPE Victoria and NSW Council for Intellectual Disability, as well as the Agency for Clinical Innovation (NSW Health) and the Department of Developmental and Neuropsychiatry (3DN) (Department of Developmental Disability Neuropsychiatry, 2014). Agencies who have developed mental health information for people with intellectual disability highlight the need for more resources, and wider distribution. The development of inclusive or targeted health promotion material is recognised as an area requiring further attention in the healthcare sector, particularly due to persistent disparities.

It is acknowledged that people with intellectual disability are not targeted in broad preventative health projects (Chinn, 2014; Naaldenberg et al., 2013; Carmeli and Imam, 2014; Lennox et al., 2012) and often rely on healthcare workers for preventative health

information (Taua et al., 2012). This is relevant for all aspects of health, including emotional and mental well-being, particularly in the light of the benefits of preventative work for people who experience mental ill-health (Jorm, 2012). Although recent decades have seen an increase in community mental health literacy projects, this was not reflected in the availability of accessible information (Jorm, 2015b; Wei et al., 2015; Galton et al., 2010).

## 2.4 Using an integrated health literacy framework to explore easy read about mental health

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Using concepts from health literacy to explore the impact of accessible information for people with intellectual disability has been limited, but has potential to deliver great insight (Chinn, 2016). The relationship between easy read, information access and service systems is complex and would benefit from further exploration within a framework such as Sørensen et al.'s (2012) integrated health literacy framework.

The findings of this review reveal that very little is known about how easy read is used in a health setting and even less in mental health. Many agencies and service users promote easy read as a tool to enable information access. However, how it is used is not clear. The use of a health literacy lens shifts the discussion from a technical focus on the design features of easy read documents to incorporate the complex array of factors which effect access to information. The use of an integrated health literacy framework exposes the gaps in knowledge about how easy read is used to enable people to access, understand, appraise and apply health information. It also highlights the potential impact of accessible information on broader health outcomes. Finally, health literacy acts as a framework for analysing the impact and complexity of communication exchange and the relationships surrounding it.

The relationship between accessible information and health outcomes illustrated in the integrated health literacy framework highlights the urgency to learn more about what makes information accessible for people with intellectual disability. The model demonstrated that tailored, accessible information, a right articulated in the UNCRPD, has potentially far reaching implications for health outcomes. These implications are particularly relevant for people with intellectual disability and mental health issues due to the acknowledged health disparities and problematic service access described in Chapter 1.

The relationship between health information and health outcomes has implications for how services are structured to support access as well as how accessible information, such as easy read, is produced and used. This association underscores the need for further empirical research about how easy read information about mental health is used to enable access for people with intellectual disabilities. This research seeks to further explore and define this gap in knowledge and add to the limited evidence base about easy read.

#### 2.4.1 Research questions

The knowledge gained from this scoping review confirms the gap in understanding about using easy read about mental health. The findings provided a platform for further investigation of practices that enable people with intellectual disability greater access to mental health information.

The following research questions were derived from the literature and context described in Chapters 1 and 2 to guide this research:

*How is easy read used to make information about mental health more accessible for people with intellectual disability?*

- 1. How does the current positioning of easy read in policy enable information access within mental health services?*
- 2. How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?*
- 3. How do people with intellectual disability and the people who support them use easy read?*

These research questions incorporate a breadth of enquiry to incorporate the individual experience of service users and providers, as well as the role of governance structures and representation of rights. The integrated health literacy framework is used to guide the research design and analysis to answer these questions. The next chapter outlines the research plan and methods used in this thesis.

## CHAPTER 3: METHODS

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This research was undertaken during a time of significant change in the Australian disability landscape. The move towards greater personalisation of services makes accessible information crucial to planning and service models. This chapter applies the evidence in Chapters 1 and 2 to explain the foundations underpinning this research (methodology) and then present the project plan (methods). The overarching research question guiding this enquiry was:

*How is easy read used to make information about mental health more accessible for people with intellectual disability?*

The chapter has five sections. Methodology is explored first (3.1), then methods are outlined (3.2). In Section 3.4, research integrity, quality and ethical considerations are examined, and the chapter concludes with a brief discussion of the limitations of the research approach.

### 3.1 Methodology

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The right to accessible information articulated in the UNCRPD is a foundation of this research. The recognition of agencies' responsibility to provide equitable systems for universal access and devise processes which respond to difference underpins this exploration. This research required an approach that could support a rigorous analysis of the issues surrounding the right to information within the complex disability and mental health services described in Chapter 1.

The epistemological position underpinning this research recognises the connection between the person, society and governing constructs such as policy or law. A critical realist approach was adopted to accommodate exploration of both societal structures and the experiences of people who live and work within these structures (Bryman, 2012, p. 29). Critical realist approaches to social theory and research build on the work of theorists such as Roy Bhaskar and Margaret Archer (Bhaskar 2016; Archer 2013). The critical realist ontology describes both the external 'truth' or structures that frame the social world, and the individual experiences which occur within these structures (Archer 2013). This understanding incorporates elements of both positivist and interpretivist or constructionist approaches (Bryman 2012). For this research, a critical realist position encompasses both agency responsibility to support staff to facilitate access, alongside the personal challenges which impact the ability of individuals to access and understand information.

The incorporation of both structural and individual considerations in the research approach is also consistent with a critical realist approach to understanding disability. Shakespeare characterises disability as a relationship which incorporates both individual realities of pain

and impairment alongside societal structures (Shakespeare, 2014). This understanding enabled the incorporation of elements from both the traditionally polarised medical and social definitions of disability (Shakespeare, 2014). A critical realist approach was useful when considering the characteristics of current service models and the selection of suitable research methods. The incorporation of both individual and societal factors as causes of disability underlined the importance of creating opportunities to gather information about both governance structures and lived experience.

Two key elements of the current service and research context outlined in Chapters 1 and 2 influenced the research focus and design. The first was the uncertainty surrounding the changes for both service users and providers in the context of the introduction of the NDIS (see Terms used, p. 12). This uncertainty had potential to impact data collection as agencies implemented new service models and developed documentation. These service changes highlighted the need for an agile research approach which could explore experiences in a changing system (summarised in 3.1.1). The second element that impacted the research design was the importance of information in personalised service systems. The need for understandable information stands at the centre of personalised models and provides greater impetus for research in this area.

As indicated in the review of the literature (Chapter 2) there has been little research, qualitative or quantitative, which has explored how easy read about health and particularly mental health was used. The inconsistencies in the literature about the definition of easy read and its effectiveness is not reflected in the use of easy read overseas, or in calls for increased availability. Disability groups are often vocal advocates for increased availability of



easy read resources, as described in Chapter 1. This research explores the disconnect between evidence about easy read and what happens in practice.

The combination of values, the current upheaval in disability support, and ambiguity in the research landscape influenced the chosen research approach. The lack of evidence about easy read development, effectiveness and use, current policy change and historic disparities have informed the research design. These contextual considerations have led to an exploratory research approach, where the focus was to explore what is currently occurring, rather than evaluating the efficacy of a specific easy read strategy or tool.

### 3.1.1 Research approach

The research sought to articulate policy structures and their representation of the rights outlined in the UNCRPD, and to explore the impact of these structures on agency practices, service providers and service users in the Australian setting. Qualitative enquiry within the critical realist frame described above was a good fit for this study for several reasons. Firstly, the complex nature of the easy read research landscape described above required flexibility to create iterative tools for data collection and the reflexivity of qualitative tools was well suited (Bryman, 2012). Secondly, as little is known about the subject area, a qualitative approach allowed for more thorough and iterative exploration. A qualitative approach can also validate the experiences of people impacted by a lack of access, voice and opportunities to explore their experience (Beail & Williams, 2014). This was an important consideration in the project design. Finally, a qualitative approach gave flexibility to work with various groups and accommodate varied communication needs as required (Hollomotz, 2018; Beail & Williams, 2014).

### 3.1.2 Other methodological approaches considered

Alternative methodological approaches were considered, and decisions about the chosen methodology were both ideological and pragmatic. The initial intention was to use an established model of enquiry to incorporate both service user interaction and agency governance. However, a suitable option to integrate the focus on easy read alongside governance structures within the time constraints of a PhD was not readily available.

Grounded theory and institutional ethnography were both considered as methodological approaches prior to finalising the research approach taken (Bryman, 2012).

Interviews using a grounded theory approach would have provided deep insight into the experience of information access of service providers and service users (Glaser, 1967). This approach would have supported exploration of the experience of rights and the relationship between service user and provider. However, grounded theory methodology would not have been the most suitable for exploration of the interaction between policy, agency procedure and service users.

An institutional ethnography framework (Smith, 2006) was also considered as it offered insight into the individual experience within the service provision context. However, the focus on a distinct strategy such as easy read would not have been possible in this model as institutional ethnography was reliant on more inductive strategies (Smith, 2006). Similarly, the approach employed by Lipsky in the exploration of street-level bureaucracy had potential to enable a greater understanding of the service user/provider interplay, yet did not lend itself to a predetermined focus on accessible information (Lipsky, 2010).

Additionally, while a detailed ethnographic study at a single site would have enabled a more exploratory focus, it may not have revealed sufficient data if the site did not apply extensive

accessible information practices. An ethnographic study has potential to illuminate issues surrounding information access and may have been preferable if suitable sites were available within the required timeframe. For this research, multi-site study was selected to enable access to diversity in practice, and this outweighed the possible advantages of a more inductive ethnographic approach (Yin, 2012).

## 3.2 Research methods

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A bespoke, qualitative mixed-methods design was adopted (Watkins, 2015). This has resulted in a study which incorporates both inductive and deductive methods for data collection and analysis. An exploratory, qualitative mixed-methods approach was devised, drawing on varied data types, collection methods and analyses. Semi-structured interviews alongside qualitative policy analysis enabled a rich understanding of the processes surrounding easy read use to be captured (Bryman, 2012; Watkins, 2015). Figure 2 represents the three phases of data collection.

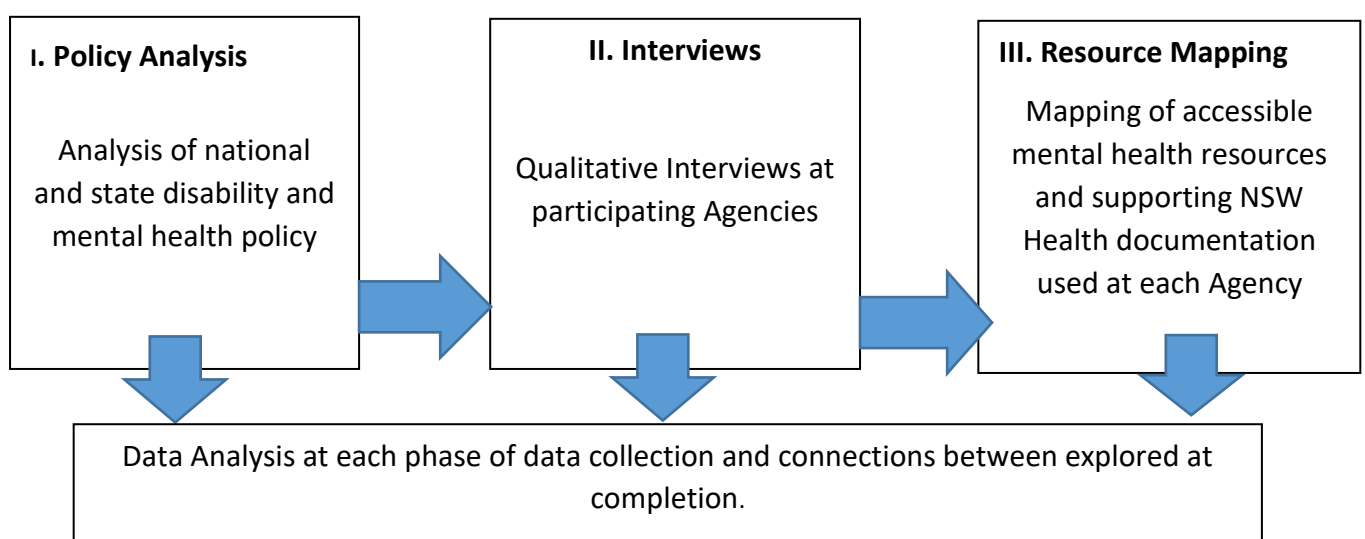


Figure 2 Data collection phases

As illustrated in Figure 2, policy analysis took place prior to the interviews at the Agencies, however, this was not a reflection of data priority (Watkins, 2015). The decision to conduct data collection in this order served two purposes. This order provided an opportunity to gain insight into service governance prior to entering the field. Conducting the policy analysis first also allowed time to recruit agencies and to gain ethics approvals for interviews while collecting and analysing policy data.

As described in previous chapters, an integrated health literacy studies lens was used to examine easy read use and bring together the varied data types included in this study. The integrated health literacy framework (Sørensen et al., 2012) incorporates the complexities found in mental health, disability and easy read spheres of study across data types. This model is a useful scaffold for understanding easy read in a health information context as it enables consideration of a complex array of individual and broader societal factors.

All data collection phases contributed to answering the overarching research question:

*How is easy read used to make information about mental health more accessible for people with intellectual disability?*

Each phase focused on the research questions outlined in Table 3:

**Table 3: Research questions and data collection phases**

Research question guiding enquiry	Data Collection Method
RQ 1 How does the current positioning of easy read in policy enable information access within mental health services?	Policy analysis Resource mapping Interviews
RQ 2 How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?	Resource mapping Interviews
RQ 3 How do people with intellectual disability and the people who support them use easy read?	Interviews Resource mapping

### 3.2.1 Selection and recruitment

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A purposive recruitment approach was used to invite appropriate agencies to participate (Bryman, 2012). The purposive approach ensured that this research included varied agency types to enable data collection from participants with a diverse range of experiences and expertise. Agencies providing mental health services to people in a geographic region, including people with intellectual disability were approached, as well as specialised services. It was recognised during the initial recruitment phase that the participating generic mental health agencies were unlikely to have many patients with intellectual disability during the timeframe of this research. A non-NSW health agency was also recruited to enable the experiences of people with intellectual disability to be included in this research.

The Agencies were central to each phase of data collection and recruitment. Recruitment of staff and service users was conducted after an agreement was reached with appropriate managers, and relevant ethics approvals had been obtained. The process undertaken to recruit agencies is outlined below along with a description of participating sites. The characteristics of individual participants follows the agency descriptions.

i) Agency selection

This PhD research was part of a larger study that included partners from NSW government and service providers. These partnerships were used as a platform for recruitment.

Non-NSW Health agency (Agency 4): One of the NHMRC partnership agencies that created and used easy read was approached to invite them to recruit staff and service users to participate in the research. This Agency was approached in order to include people with intellectual disability and people who support them in the study. This Agency had many members with extensive experience using and developing easy read. Agency staff distributed information about the research and promoted it in the Agency newsletter to recruit staff and members. Details of the interview participant recruitment is outlined at iii).

NSW Health agencies (Agencies 1-3): Existing networks, including all metropolitan Local Health Districts (LHDs) involved in capacity building to meet the needs of people with intellectual disability were invited to participate in this research. The criteria listed in Table 4 were used to determine eligibility:

**Table 4: Agency inclusion and exclusion criteria**

<i>Inclusion Criteria:</i>	NSW Health entities providing health services, including mental health, to people with intellectual disability.
<i>Exclusion Criteria:</i>	agencies that do not provide health services to people with intellectual disability.

Invitations were distributed via email and three Local Health Districts (LHDs) responded positively. The LHDs were a mix of generic and specialised services which was valuable for this research. These three LHDs were visited to discuss participation and begin the NSW Health ethics approval process, outlined in Section 3.3. Once approval was granted, meetings were held with managers to promote the research and begin recruitment of managers and staff (Appendix 1). Individual recruitment methods are outlined at iii) after the Agency descriptions.

## ii) Agency descriptions

All the agencies that responded positively to the email took part in the study. The agencies included in the study varied in size and focus, as described below.

### Agency 1

Agency 1 was a large city public mental health service with several campuses, and offered both community-based and inpatient services. All interview participants from Agency 1 worked in inpatient mental health services at one city site. The participants worked across acute mental health inpatient units with both voluntary and involuntary patients. Some staff

provided outpatient medical consultations in a clinic. Interview participants included medical, nursing and allied health staff. No service users participated at Agency 1.

Agency 1 was in the process of establishing a new model of service provision to provide support for people with intellectual disability accessing mental health services. The interview participants at Agency 1 included two medical staff from this newly established specialised intellectual disability mental health team, as well as staff working in generalist mental health inpatient services. Many staff had worked in the generalist mental health service for many years, whereas those from the newly established team had been at Agency 1 for only a couple of months. See Table 12 (Appendix 2) for participant characteristics by Agency.

#### Agency 2

Agency 2 was a large, city-based public mental health service which had several campuses and offered both community-based and inpatient services. Staff from a range of mental health services across Agency 2 participated. The participants included staff in community-based roles as well as people who worked with people in inpatient mental health units. Staff worked across a range of age groups, from services targeted to teenagers to services for older people. The suite of options included peer support services. The inpatient units included some with a short-stay, acute focus for involuntary patients as well as units for voluntary admission. Some staff provided support across inpatient and community services and others had roles in one service setting. Agency 2 also included one staff member in an intellectual disability mental health clinical coordinator role. No service users participated at Agency 2.



The roles and length of employment varied widely between services at Agency 2. Some services had a majority of staff who had been employed for a long period of time (some 30 years +) and at other services all staff interviewed had been employed at the service for less than two years. Table 12 (Appendix 2) has a summary of detail describing participant characteristics.

### Agency 3

Agency 3 was a publicly funded, specialised paediatric intellectual disability health service and participants were from two services. One service was a specialised intellectual disability mental health team for children and younger people, at a hospital, and the other service was a specialist intellectual disability health clinic for children and younger people in a community setting. Both locations provided services to children and their families.

The primary function of the hospital-based service was to provide psychological services to children aged 0-18 years with intellectual disability or delay and a secondary mental health concern. The team delivered psychiatric, psychological and limited allied health consultation to children within the hospital and as outpatients. The team also offered consultation with other service agencies and hospital departments to deliver integrated, ongoing care.

The community-based Agency 3 service provided health services to 0-18 year-olds with intellectual disability. The primary roles of the team are to enhance mainstream services, provide education and address unmet needs. The staff described their team as providing a multi-disciplinary service with medical specialists and allied health staff.

The only parent/carer interviewed for this research used Agency 3's services.

Some staff had been at the community location for many years, however staff said that future funding uncertainty had resulted in many staff changes over recent months. In

contrast, the staff interviewed at the hospital tended to have been employed for longer than staff working at the community service as listed in Table 12 (Appendix 2).

Agency 4 Agency 4 was the only non-health provision Agency included in this research.

Agency 4 was a city-based advocacy organisation for people with intellectual disability. The development of accessible documentation, such as easy read, was a core role of the Agency.

The staff and service users who took part had all used and been involved in developing easy read material. Although people with intellectual disability were invited to take part in the research at all Agencies, this was the only Agency where people with intellectual disability participated.

Agency 4 had a relatively high turnover of staff and staff reported that funding uncertainties made it difficult to maintain consistent teams. Information about the length of staff employment is listed in Table 12 (Appendix 2).

### iii) Participant recruitment

Criteria were developed to capture the views of people with intellectual disability and staff working in both direct service provision and management roles. Table 5 outlines inclusion and exclusion criteria for interview participants. The exclusion criteria sought to avoid coercion and respect the needs of participants who may have experienced fluctuating mental health conditions. The recruitment process was guided by the National Health and Medical Research Council (NHMRC) Statement and Guidelines (National and Medical Research Council, 1999) and the consent process is described in Section 3.3.

**Table 5: Interview inclusion and exclusion criteria**

Inclusion criteria	<p>Interview Participants must have been working at or accessed services in a participating NSW Health site and have met one of the following criteria to participate:</p> <ul style="list-style-type: none"> <li>• Have lived experience as a person with an intellectual disability</li> <li>• Be over 16 years of age</li> <li>• A trusted person who the participant with intellectual disability has given permission for the researcher to contact</li> <li>• Be a parent or guardian of a person with disability who is under 18</li> <li>• Be a service provider or advocate in the field of intellectual disability</li> <li>• Be a service provider or advocate in the field of mental health</li> </ul> <p>Or</p> <ul style="list-style-type: none"> <li>• Have an intellectual disability and experience creating and/ or using easy read (recruitment via Agency 4)</li> </ul>
Exclusion criteria	<p>For interview participants (note: whilst these exclusions related to persons with intellectual disability, some could also relate to other participants such as parents, guardians or trusted persons):</p> <ul style="list-style-type: none"> <li>• Currently active symptoms of psychosis or mania</li> <li>• Severe major depressive episode, anxiety disorder or other mental illness</li> <li>• Under 16 years of age</li> </ul>

There were 49 interview participants across 4 Agencies. The participants included allied health staff, nursing staff, medical practitioners, service users, one paid carer who accompanied a service user and one parent who attended an interview without her son.

Ethics approval was gained for inclusion of people with intellectual disability, but there were no people with intellectual disability accessing service during the project. Recruitment at Agency 3 yielded one parent. The generalist services were not able to provide data about how many people with intellectual disability accessed their services.

Table 12 (Appendix 2) summarises the research participant characteristics by Agency.

### 3.2.2 Policy analysis

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This policy analysis was designed to review the way that accessible information was represented in the policy which governed the mental health Agencies included in the study. The aim of the review was to understand more about the ways that mental health policy supported staff to provide access to information.

Dew et al. (2018) conducted an analysis of the representation of people with intellectual disability in Australian mental health policy, concluding that: ‘as a policy issue, the mental health of people with intellectual disability is poorly recognised and as a result is inadequately addressed’ (Dew et al., 2018, p. 142).

The framework devised by Dew et al. (2018), and their findings about the representation of people with intellectual disability, were used as a starting point for this PhD analysis. Their findings about the representation of people with intellectual disability provided the impetus for a more focused examination about the way that accessible information is represented in policy. Dew et al.’s work had a focus on representation, incorporating policy development and processes. This PhD policy analysis investigates the way information access and easy read is represented in the UNCRPD and reflected in relevant Australian policy.

The work of Fisher et al. (2019) was informative in developing a systematic search strategy to conduct a content analysis. This analysis incorporated both the specific text and policy context using five steps:

- i) Gathering relevant documents

Policy which governs mental health service provision for people with intellectual disability in NSW was included in the review. Policies included health and mental health policy documents, procedures, guidelines and directives as well as disability policy. A definition of policy is included in the Terms used (p. 12) and policy analysis findings appear in Chapter 4. Table 6 lists inclusion and exclusion criteria for the policy analysis.

**Table 6: Policy analysis inclusion criteria**

Inclusion criteria	<ul style="list-style-type: none"> <li>• Mental health policy documents</li> <li>• Strategic disability policy documents</li> <li>• General health policy documents that included mental health</li> <li>• NSW mental health policy directives available on NSW Health website and directly related to patient communication/interaction</li> <li>• Policy directly related to mental health service provision at the Agencies, available online or provided by participating Agency staff</li> <li>• Spanning 2007 – 2017 and in current use</li> </ul>
Exclusion Criteria	<ul style="list-style-type: none"> <li>• Policy that not related to mental health service provision</li> <li>• Policy outside of the dates specified</li> </ul>

	<ul style="list-style-type: none"> <li>• Policy not relevant to services in NSW</li> </ul>
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An internet search was conducted to obtain Commonwealth and NSW Disability, Health and Mental Health policy. Once collated, the NSW Ministry of Health was consulted to ensure the list of policy included was accurate, current and comprehensive.

Agency policy officers in the three participating LHDs were consulted to obtain a comprehensive suite of documents. During interviews, staff at participating Agencies were asked to identify policy directives which directly impacted their Agency's practices and to provide relevant documentation (See Section 3.2.1 for Agency inclusion criteria, descriptions, and interview methods, and Appendices 8 and 9 for interview questions).

A master list of all policy was collated, and each document was given an identifier and a separate electronic folder to house relevant search evidence and summaries. A list of all policy analysed is provided in Appendix 3.

## ii) Search strategy

A list of key words was defined to inform the document searches. This list was developed to include key concepts from the UNCRPD, literature review findings (Chapter 2), and the concepts of accessing, understanding, appraising and applying health information described in the integrated health literacy framework (Sørensen et al., 2012). A list of key concepts and corresponding search terms is provided in Appendix 4.

Two staff at the Social Policy Research Centre, UNSW (SPRC), relevant NHMRC Partnership members and the UNSW library staff were consulted to ensure the search terms were

relevant and suitable. The search terms were piloted with 8 documents before commencing the review.

iii) Policy content analysis

NVivo 11 (QSR 2015) was used to search the policy documents. Searches included complete words, stem or root words, synonyms and the surrounding paragraph to ensure relevance. Findings were retained in NVivo folder format and a summary of findings was developed using Microsoft Excel. A sample from the Excel spreadsheet is presented in Appendix 5.

iv) Recording policy analysis findings

Two templates were used to record a summary of findings. Template I (Appendix 6) was developed to correspond with the key words about information access and used to analyse all policy documents. Template II (Appendix 7) analysed the representation of people with intellectual disability in policy; this was a replication of the template developed by Dew et al. (2018). Template I was used to analyse all policy, and Template II only for policy not represented in Dew et al.'s findings. This approach was taken to generate comprehensive data about each policy and to avoid duplication.

v) Synthesising policy analysis findings

The findings recorded on each of the templates were analysed to identify themes according to policy type and purpose. A Microsoft Excel spreadsheet (sample Appendix 5) summarised the policy and facilitated analysis and synthesis. The findings are outlined in Chapter

### 3.2.3 Interviews

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Individual interviews were the most appropriate data collection tool for this research as they provided the opportunity to explore personal experiences. Exploring and clarifying issues with participants was particularly important as easy read was unfamiliar to participants and the service environment in a period of transition (see Chapter 1). Semi-structured interviews were a suitable data collection method for this study as they enabled tailoring for individual difference and prompting as required. The semi-structured interview style enabled exploration within the integrated health literacy framework and provided the opportunity for responsive questioning and follow up.

The focus of the interviews was the use of easy read in the context of the chosen Agency. The interview question guides incorporated relevant findings from the policy analysis and the objectives of access, understanding, appraising and applying information found in Sørensen et al.'s integrated health literacy framework (Figure 1). Supervisors and the NHMRC partners were consulted to review draft questions. Questions were piloted with colleagues unfamiliar with the project. Interview guides are attached in Appendices 8 and 9.

#### i) Informed consent for interviews

Participants were recruited as described in Section 3.2.1. The consent process for staff and service users differed as outlined below.

*Agency Staff:* Following appropriate site-specific ethics approval and relevant approvals from Agency management, staff received information about the research at a briefing



session conducted by the researcher during a staff meeting. Staff were encouraged to consider their involvement and respond to the invitation to take part. The decision to be involved was made independent of the Agency managers, and staff were assured that their decision would not impact their employment. This process was to avoid coercion or perceived pressure. Staff were asked to complete a written consent form at the time of interview (sample Participant Information Sheet and Consent PISC Appendix 10-15). PISC forms were required to be amended for each health Agency to include the relevant logo and contact details. Identifiable PISCs with Agency logos have not been included in the appendices to avoid identification of specific Agencies. The information about the project did not vary.

*Service Users:* To minimise the potential for service users to feel coerced or under pressure to take part and to ensure informed consent was obtained, recruitment of service users followed a three-step process:

Step 1: Staff distributed project information (Appendices 16 and 17), relayed eligibility criteria, and invited service users to contact the researcher if they wished to take part. A contact person volunteered to discuss questions with people with intellectual disability at the Agency and provided support as required. The staff contact person offered people with intellectual disability support to make contact with the researcher or made contact on their behalf. As described above about the staff PISC, service user PISC forms were amended for each health site to include the relevant logo and contact details.

Step 2: Interested research participants or their advocates or guardians initiated contact in person at the Agency or via the contact details included on the study advertisement

(Appendices 16 and 17) to express their interest in participating in the study and to ask any questions they had about the research.

Step 3: If the participants met eligibility criteria and wished to continue with their involvement in the research, they were invited to participate in an interview. The appropriate PISC (Appendices 10-13) was used to guide this discussion and a carer/guardian was included to support communication as required and provided with a PISC if appropriate (Appendices 14 and 15). During this time, participants were given the opportunity to ask questions about the research. Throughout this discussion participants' behaviour was observed to gauge any distress or confusion regarding the research process (NHMRC Statement 2.2.3,1.7). For all participants, a trusted person was welcome to be included in the interview at the request of the person with intellectual disability. Only one participant chose to have an advocate present.

As per NHMRC Statement section 4.5.5 and 4.5.6 appropriate communication strategies were employed and time consideration was taken for their capacity to consent. Easy read versions of the consent and information sheets were produced with and without pictures and made available as required (Appendices 8 and 9). Verbal consent was also available to be used as needed and was only used with one participant over the phone (Appendix 18).

Additionally, at the time of the interview, the researcher ensured that the person with intellectual disability comprehended the process and consented for the interview to proceed, with the assistance of the trusted person when present. Service users who chose to participate were reimbursed with a \$40 voucher to acknowledge their time and to cover any expenses associated with the research study. Participant characteristics are described in Appendix 2.

## ii) Interviews

Semi-structured qualitative interviews were conducted at four Agencies. Interviews took place between May 2017 and February 2018. In total 49 participants took part in interviews and a summary can be found in Appendix 2.

A semi-structured approach enabled both inductive and deductive enquiry. This reflected the methodological commitments outlined above and enabled the integrated health literacy framework to be used to guide the subject areas covered. The questions provided in the interview guide were intended to provide structure and guidance to the researcher (Appendices 8 and 9). For some participants all questions were required to prompt responses or to maintain focus. However, other participants told of their experiences in a conversational style and required minimal prompting to cover all areas of enquiry and not all questions were needed to elicit the required information.

Participants were able to choose the location of interviews. Two participants chose to be interviewed over the phone and the remaining 47 interviews took place at the participating agencies. Agencies allocated a room or quiet space for interviews to be conducted. Staff were invited to speak to the researcher directly if they had questions about the research prior to commencing the interview. One interview was with a carer/supporter without the person with intellectual disability present.

All interviews were audio recorded with participant permission. A backup recorder was used; however, two interviews were documented with handwritten notes immediately after the interviews due to recorder/battery malfunction. Interview lengths ranged from 9 to 56 minutes. See summary of interview participants in Appendix 2. Three joint interviews were

included in the data. The data was considered separately for each participant in the analysis as the participants did not always express common views.

### iii) Interview data analysis

Data analysis was carried out using iterative categorisation to explore the themes evident in the data in relation to the integrated health literacy framework (Sørensen et al., 2012).

Iterative categorisation was used as it offers a rigorous staged approach to analysing qualitative data and is appropriate for use with deductive studies with prescribed areas of interest (Neale, 2016). The staged process and definition of each stage instilled greater confidence in the repeatability of the analysis process across multi-site data collection.

Data was analysed as it was collected. Data was coded and analysed in reference to all previously analysed Agency data. Iterative categorisation has eight stages and these were conducted in order for each Agency:

*Stage 1: Transcription* (and collation of any other textual data.) The interviews were all recorded and transcribed verbatim. Fourteen of the interviews were transcribed by an external transcription service with an appropriate confidentiality agreement as approved by the NSW Health Ethics Committee. For interviews with more than one participant, the interviews were transcribed and then data for each participant was separated to be considered as individual participant data.

*Stage 2: Familiarisation* All recordings were listened to on a number of occasions (some for the purpose of transcription), and any interviews transcribed by an external service were listened to numerous times to correct any irregularities.

*Stage 3: Anonymisation* Neale et al. (2016) suggested that numerical, systematic naming conventions be established for anonymisation and ease of recognition, i.e. Agency, number of participants and role, e.g., 1.11.S. A Microsoft Excel spreadsheet was created as a summary of all participants and interview data such as interview time length and code number. Where extended examples or scenarios have been presented in this thesis, a pseudonym has been used.

*Stage 5: Logging & filing/storage* NVivo 11, Microsoft Excel and Microsoft Word files were used to collate and store data. All data was stored according to UNSW guidelines. All identifiable information and participant demographics were stored on Onedrive and an identifier allocated to each recording. This identifier indicated Agency type and was consistent across all data for each participant. Paper copies of consent forms were stored at UNSW in a locked cabinet. For further information about anonymisation see Section 3.4.

*Stage 6: Data coding* was deductive and inductive and was conducted manually using NVivo 11 to examine, collate and store the interview data. A coding framework was developed using the integrated health literacy framework objectives to access, understand, appraise and apply information. It became apparent that the access and appraise codes contained overlapping concepts and a coding tree was developed to incorporate more specific aspects of appraisal and application. As data was coded, this coding schemata was expanded to incorporate the overarching codes defined in Figure 3.

Concepts from Health Literacy Framework	Categories Developed
Access	1. <i>Agency</i> : Agency role or individual participants 's place within the Agency.
	2. <i>Accessing Information</i> : the process of obtaining information
Understand	3. <i>Understanding Information</i> : the ability to comprehend information accessed
	4. <i>Easy Read</i> : information about easy read documents- development and use
	5. <i>Health Appointments</i> : interaction between a health practitioner and service user
Appraise and Apply	6. <i>Relationships</i> : data about interpersonal relationships
	7. <i>Risk and Choice</i> : issues related to autonomy and self-determination in decision making
	8. <i>Mental Health Information</i> : information about mental health conditions or service issues
	9. <i>Other</i> : any data that may be relevant but did not fit in the categories above.

Figure 3 Data coding tree

Within each of these codes, further groupings or sub codes (NVivo child nodes) were used as required at each Agency. The codes did not relate solely to each area of accessing, understanding, appraising and applying information. For example, Code 8: *mental health information* and 4. *easy read* impacted all areas and separate codes were used to facilitate a focus on the research question.

Transcriptions were coded and analysed by Agency, chronologically as interviews were conducted. Coding decisions were discussed and cross-checked with Professor Karen Fisher , research supervisor. Data was analysed and stored by Agency. This was both a

methodological and pragmatic decision as the NSW Health website listed specific ethics approvals that had varied timeframes for approval.

*Stage 7: Preparation for analyses* Once all coding for an individual Agency was complete the data from each NViVo node was copied and pasted from NViVo to a Microsoft Word document. Each Agency had a designated identifier which was included in all data names and a folder was created in Microsoft Word to keep all transcriptions and analysis. An example of the system employed is included in Appendix 19.

*Stage 8: Analysis* Descriptive analyses were conducted first. Using the techniques described by Neale (2016), a split screen was used in Microsoft Word to further distil findings and summarise within the node. Chunks of information stored as 'raw data' in code folders were read through and grouped with like to create a summary. A screenshot of a 'split screen' data has been provided as an example in Appendix 15. The decision to analyse themes by Agency assisted in developing an understanding of Agency-specific practices and characteristics.

The integrated health literacy framework provided a scaffold for interpretive analysis. However, this process was both inductive and deductive, and so it was not limited to the codes designated by the framework. The development of codes is described in *Stage 6* (above). Once all Agency coding was complete, findings were collated into a summary document for each Agency. Themes and commonalities within and between the data collection sites were identified. Further interpretative analysis was conducted when seeking to explore connections between findings from other data collection phases (i.e. policy and resource mapping, see Figure 2)

### 3.2.4 Resource mapping

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The aim of the resource mapping was to facilitate further exploration of the relationships between policy, resource availability and Agency practices. This mapping exercise provided background for RQ 1 and 2 and acted as a platform for these questions to be explored further in the chapters which follow.

*RQ 1 How does the current positioning of easy read in policy enable information access within mental health services?*

*RQ 2 How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?*

i) Gathering relevant accessible documents

**The focus was on the resources that staff used and had available for future service users. Table 7 summarises inclusion and exclusion criteria for mapping available documents.**

**Table 7: Inclusion and exclusion criteria of documents mapped**

Inclusion criteria of documents	All text-based documents provided or used by the 4 Agencies that were developed to incorporate the communication needs of people with intellectual disability.
Exclusion criteria of documents	Communication devices or systems provided by service user or their supporters Documents in standard language formats Documents in languages other than English.

An online search of NSW mental health documentation was carried out. After the online search, managers and Agency staff were consulted in interviews, via phone contact and



during Agency visits to ascertain which accessible communication resources were available at their Agencies. Data collection was primarily via semi-structured interviews (see Appendices 4 and 5 for interview schedule) when staff were asked to describe easy read accessible documents they had used, or seen in use at their Agency (interview participant characteristics, Appendix 2). The limited resources available to map prior to interviews was both a constraint that required consideration and a relevant finding. The change in approach resulted in a rich exploration of the limited resources available in the interview setting and the findings are presented in Chapter 5. This limitation is discussed in section 3.4.

ii) Developing a taxonomy for mapping resources

There was no readily available framework for resource mapping fit for this research in the literature. The work of Ames et al. (2015) mapping vaccination information resources was instructive, along with the principles outlined in Hill et al.'s (2011) work on Health Literacy. At the commencement of the study it was unclear how many easy read resources would be included and therefore the design features of a framework were difficult to articulate prior to data collection. Hill's taxonomy was the option planned for use. However, the level of detail obtained during data collection was not sufficient to classify documents according to the categorisations developed in Hill's work.

After reviewing similar projects, a taxonomy was developed to map the availability of easy read resources in participating agencies. The concepts outlined by Ames et al. (2002) were informed by Sørensen et al.'s (2012) integrated health literacy framework. The taxonomy

developed to map resources incorporates Sørensen et al.'s (2012) domains of healthcare, disease prevention and health promotion. In addition to these domains the categories of Agency forms and policy have been added.

A distinction has also been made between documentation that is readily available as a standard easy read guide or tailorable resource, and bespoke options developed for a specific service user. This distinction was made as staff at all Agencies saw distinct advantages and disadvantages to standardised vs bespoke information.

Sørensen et al.'s definitions of healthcare, disease prevention and health promotion were used as the basis of the categories developed to map resources (Sørensen et al., 2012, p. 10). A description of each of the categories developed for categorisation has been listed in Table 8.

**Table 8: Taxonomy categories**

Taxonomy category by purpose	Definition	Examples
Agency policy	Documents devised to guide Agency procedures/processes	Complaints procedure, Privacy policy
Agency forms	Documents to be read and completed by service users to participate in the service, often mandatory	Consent form, planning documents
Healthcare – standard	Information readily available to staff to provide an individual with information about a medical condition, symptoms or hospital stay that is in an accessible format or readily tailorable	Fact sheet about anxiety, clinic information
Healthcare – specific	Information developed by the Agency for an individual with intellectual disability about their medical condition, symptoms or hospital stay	Social story about an appointment, easy read version of hospital ward schedule
Disease prevention – standard	Information about health-related behaviour changes or intervention that is in an accessible format or readily tailorable	Exercise and nutrition brochure
Disease prevention – specific	Easy read information developed by the Agency for an individual with intellectual disability about health-related behaviour changes or intervention	Tailored exercise plan with individualised goals
Health promotion	Easy read information about the broader determinants of mental health and well-being	Easy read flyer about reducing stress

iii) Recording findings of resource mapping

The documents located at each Agency and any staff reflections were mapped by Agency according to the categories in the taxonomy above.

Information was categorised according to 3 classifications:

1. staff were unaware of this resource being used or available at their Agency
2. at least one staff member had used or seen this resource used at their Agency
3. over half of staff interviewed indicated that they had seen or used this resource

Findings from each site are summarised in Chapter 5.

## 3.3 Research integrity

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### 3.3.1 Assessing project quality

Using qualitative methods often presents a challenge when assessing research validity or credibility, as measures used in the quantitative paradigm are not suited to interpretive or qualitative work (Neale, 2016). In the qualitative sphere, much of what constitutes good quality enquiry aligned with ethical practices and decisions in both data collection and analysis and these can be difficult to measure. Lincoln (2011) asserts, in the SAGE qualitative research handbook, that there is an emphasis on trustworthiness as a paradigm rather than rigour. Lincoln acknowledges the importance of making intrinsic values explicit and maintaining authenticity in the research process (Lincoln in Atkinson and Delamont, 2011, p. 4). The acknowledgement of values and positionality at the commencement of this thesis (Chapter 1) and throughout evidences this commitment to transparency. While this acknowledgement of transparency in the values underpinning the research is essential, there is also merit in providing evidence of the quality of the research design and implementation.

In addition to the challenges associated with assessing the quality of qualitative research, assessing mixed methods projects has also been contested. The SAGE research handbook sets out a quality framework for mixed methods studies. The key concepts in the quality

framework are from Tashakkori and Teddlie (2016). Tashakkorie and Teddlie (2016) present eight domains of planning quality, data quality, design quality, interpretive rigour, inference transferability, reporting quality, synthesizability and utility. The first four are of most relevance for this research. Specific aspects of the research design are highlighted in Table 9 using the first four domains of the SAGE handbook's framework (Tashakkori and Teddlie, 2016

**Table 9: Assessing project quality**

Domain	Features of the research
Planning quality (literature review, justification for approach, transparency and feasibility)	<ul style="list-style-type: none"> <li>• A comprehensive literature review was performed to inform research design and focus (Chapters 1 and 2)</li> <li>• The research was planned under supervision of PhD supervisors and other scholars consulted throughout the process</li> <li>• University graduate research panel reviewed endorsed research feasibility</li> <li>• The rigorous UNSW and NSW Health ethics approval processes have ensured that this research was planned and designed in accordance with ethical practices.</li> </ul>
Design quality - Transparency (Suitability, strength and rigour)	<ul style="list-style-type: none"> <li>• Clear rationale for design is outlined in this thesis</li> <li>• The ethics approval processes (UNSW and NSW Health) involved scrutiny of all documentation. This included a full description of all phases of the research and review of all participant information to ensure that the project design was ethical and feasible within the timeframes.</li> <li>• A clear project plan was developed prior to data collection. This was endorsed by a number of HRECs who were satisfied with the soundness of the project design.</li> <li>• Positionality was acknowledged throughout the research and researcher values were explicit in the design.</li> </ul>
Data quality (Transparency, rigour in design)	<ul style="list-style-type: none"> <li>• Clearly articulated methods have been described and used to inform all phases of data collection</li> <li>• Data collection methods were informed by the literature</li> <li>• Data was collected and stored according to UNSW policy and HREC approval.</li> </ul>
Interpretive rigour (conclusions based on findings, transparent process, consistent with theory)	<ul style="list-style-type: none"> <li>• Using iterative categorisation provided a step-by-step process used for data analysis which provided a transparent process for this work (Neale, 2016).</li> <li>• The use of the Integrated Health Literacy Framework provides a scaffold for findings across data collection types. The framework links data types and enables interpretation within the model.</li> </ul>

Column 1 domains as described by Tashakkori and Teddlie (2016, p. 12)

### 3.3.2 Ethical considerations

The potential vulnerability of the population involved in this research was a paramount concern in planning and conducting the research. Particularly important to consider were the dilemmas surrounding consent for people with intellectual disability, engagement of people experiencing an episode of mental ill-health, and the integral role of family or carer in enabling participation in research activities. The case study Agencies were engaged to determine appropriate participants to invite to take part in the interview phase of the research. Agency staff ensured that interviews were conducted in a manner appropriate to meet individual communication and support needs.

Consent processes and interview methods outlined in Section 3.3.3 reflect this commitment to ethical practice. The appropriate ethics approvals relevant for each Agency were obtained prior to data collection.

### 3.3.3 Ethics approval

Ethics approval was required from UNSW and NSW Health Human Research Ethics Committees (HREC) for conduct of research at the four participating Agencies. The proposed research was considered to be more than low-risk, and thus required appropriate application and consideration by the full committee at both UNSW and NSW Health for participation of the NSW Health Agencies.

This research was approved by UNSW HREC, approval number UNSW HC17146 in May 2017.

In addition, approval was gained from NSW Health to include NSW Health Agencies from the three Local Health Districts that agreed to take part in the study. Overarching multi-site approval was gained for the conduct of research at NSW Health sites from South Eastern

Sydney Local Health District HREC in June 2017 (NSW HEALTH HREC /17/POW/261). Site specific approval for the three NSW Health Agencies was obtained from relevant Local Health District HRECs between June and December 2017. An amendment for external transcription was approved in October 2017.

Copies of ethics approvals were not included in this thesis in order to maintain the anonymity of participants. Interviews were audio-recorded, and all data was stored according to UNSW's data management policy. A current Working With Children Check was obtained at the time of data collection and all screening required by NSW Health agencies was undertaken.

#### 3.3.4 Anonymising findings

In analysis and presentation of results, all Agency and individual details have been anonymised to protect participant confidentiality. Findings about staff or Agency practices have been generalised where appropriate to avoid identification. The quotes incorporated in this thesis are from across all participating Agencies. Quotes are purposefully presented in a way that limits identifying characteristics, but describes relevant participant attributes. Pseudonyms are used when vignettes or more extensive information is presented.

Local Health District (LHD) policy has been included with Agency number and policy descriptor rather than full name to retain the anonymity of participating agencies. PISCFs with logos or Agency-specific information have not been included in the Appendices to avoid identification of specific Agencies.



### 3.4 Methodological limitations

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The qualitative mixed methods design and use of the integrated health literacy framework provided an effective way to explore the research questions, however there were some methodological limitations. These limitations are described below in relation to the overarching design and each of the three data collection phases.

Firstly, it could have been beneficial to have used a more collaborative research approach, within the time constraints of the PhD candidature. Greater collaboration with people with intellectual disability, their supporters and mental health practitioners in the project design would have been useful. Such collaboration would have enabled greater consideration of the needs of each group in prioritising which data to collect and the methods of data collection. More varied data collection methods and inclusion at all stages of research development would have been ideal (Bigby et al., 2014; Milner & Frawley, 2019). A more inclusive design would be a valuable option for future work and is discussed further in Chapter 9.

Secondly, the availability of policy at the health agencies varied significantly. Two health agencies had all documentation available online and a policy manager to ensure currency of documents accessed, whereas another required a request to be sent to the policy team for access and fewer documents were made available for analysis. It was unclear whether further documentation was in use and this sample was not reliably representative of all Agency policy. The variation in policies provided and gaps in available documentation limited the conclusions that could be made about LHD-level documentation in the review.

Thirdly, the number of accessible information resources available online or via NSW Health was so limited that the mapping exercise was not possible as proposed in the initial project

design. This was primarily due to researcher assumptions about the availability of accessible information for the resource mapping data collection phase. Initially, the research design incorporated mapping of accessible or easy read resources prior to interviews. The methods were amended to incorporate resource mapping alongside interviews. The limited resources available to map prior to interviews was both a constraint that required consideration and a relevant finding. The change in approach resulted in a rich exploration of the limited resources available in the interview setting and the findings are presented in Chapter 5.

Finally, a comment about the recruitment of service users at participating agencies. The research design brought a large amount of relevant data to light, although if time were not so limited, it would have been valuable to include service users with intellectual disability from the participating agencies, in addition to staff. Ethics approval was gained to include service users, however the context of the services meant it was not appropriate to engage people currently accessing services within the research timeframes.

An additional challenge of using the integrated health literacy framework to frame findings chapters in this thesis was the potential for repetition. The option of presenting findings by Agency was considered, however, this structure also presented issues of repetition. The health literacy framework was preferable as it provided a scaffold to explore the concepts across sites and minimised the presentation of a comparative study of agency practices.

## CHAPTER 4: POLICY ANALYSIS

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The purpose of the policy analysis is to establish the way that NSW and Australian Commonwealth policy represent the right of people with intellectual disability to access information about mental health. This policy analysis outlines how information about mental health for people with intellectual disability is represented in policy, rather than exploring how policy impacts practice (Turnbull & Stowe, 2017). This content analysis examines how policy supports Agency staff to assist people with intellectual disability to access, understand, appraise and apply information. Methods are described in Section 3.2.2.

This analysis generates greater understanding of how accessible information is represented in the policy that underpins practice at the participating Agencies. Its purpose is not to provide a comprehensive evaluation of mental health policy, or to explore policy development. The findings are a backdrop for the investigation of Agency practices in the chapters which follow. This chapter includes the definition of policy used, policy background, method of enquiry and findings, with a brief discussion of implications.

## 4.1 Defining policy

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Policy resides at the intersection between principles and practice and there is often a contested, complex path to its development and implementation. Health policy is defined as:

a plan that steers the direction of investment and action designed to alleviate suffering, improve healthcare or prevent illness. It can be manifested as laws, bureaucratic edicts, practice guidelines, or more vaguely, simply as guiding principles (Cheung et al., 2010, p. 406).

This definition is suitable for the analysis as it confines policy to plans or documentation and encompasses the various forms of policy instruction provided to staff at participating Agencies.

## 4.2 Background

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Immense cultural change in the conceptualisations of disability and mental health has occurred in recent decades in Australia, and policy reflects this attitudinal shift.

Internationally, the culmination of this change is represented in the United Nations Convention on the Rights of Persons with Disability (UNCRPD). The UNCRPD represents both the end point in a long-fought battle, and a platform upon which change can be built (Kayess & French, 2008). As Australia has ratified the UNCRPD, this Convention gives a set of principles to underpin other policy and practice.

Australian disability and mental health policy preceding the UNCRPD reflects the broader shift away from exclusion to inclusion, as described in Chapter 1. Policy in both disability and mental health spheres traces the moves toward deinstitutionalisation in the 1960s/70s and the emphasis on community models of care in the 1970s/80s. The focus moved to mainstreaming services in the 1980s/90s. Since the 1990s, policy promotes models which endorse social inclusion in both spheres, and a recovery model in mental health services. The Commonwealth Mental Health Plans of 1992, 1998, 2003 and 2008 were key drivers of change in mental health practice. These Plans represented a move away from policy which instigated prescriptive regulation to a greater focus on monitoring service standards and consumer outcomes (Grace et al., 2015). This shift is also evident in disability policy (Schalock, 2017).

In the past decade there has been an increasing recognition of inadequate access to disability support in Australia. These issues were brought to the attention of the community and policy makers in two reports, namely *Shut Out: The experience of people with disabilities and their families in Australia, 2009* and the *Productivity Commission Report: Disability Care and Support, 2011*. These reports were precursors to major change in Australia's disability service sector which has culminated in the *National Disability Insurance Scheme (NDIS) Act 2016*.

The cultural changes in service provision evident in the National Disability Insurance Scheme (NDIS) have impacted the focus of disability policy. The NDIS has increased the marketisation of services and produced competition between service providers. Disability policy was once delineated by service type, and service governance remained with commonwealth and state entities. Since the implementation of the NDIS, services for people

with disability are becoming the domain of various agency types and funding for services is increasingly determined by consumer demand. There has been a growing recognition that policy needs to be not only measurable against market efficiencies or quality standards, but also embed rights-based outcomes in design (Schalock, 2017).

The review explores how the rights articulated in the UNCRPD are conveyed in Commonwealth and NSW state mental health policy in three NSW Local Health District (LHD) Agencies. There is no prescribed definition of disability or intellectual disability as a criteria for policy inclusion. Rather, the focus of this review is on communication and the scope for inclusive options such as easy read in policy. A detailed description of the methods used to guide this analysis is included in Chapter 3.

The two overarching questions guiding this enquiry are:

*How does the current positioning of easy read in policy enable information access within mental health services?*

*How are the rights relating to information access outlined in the UNCRPD represented in policy?*

## 4.3 Policy analysis findings

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Sixty-seven policy documents were analysed including the UNCRPD. The documents were divided into International, Commonwealth, State and Local Health District (LHD) levels of governance for analysis. The documents included are listed in Appendix 3. Findings are presented in each of these categories and findings are summarised in Table 17 (Appendix 20).

The term 'easy read' did not appear in any of the documents reviewed. As the exact terminology 'easy read' was not present, the findings are represented in relation to accessible information, and the broader supporting concepts of participation in decision making articulated in the UNCRPD.

The principles about accessible information articulated in the UNCRPD are outlined below.

The summary of UNCRPD principles is followed by an exploration of policy documents.

#### 4.3.1 UNCRPD and information access

The purpose of the UNCRPD is:

to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (preamble (m), UNCRPD, 2006 ).

The underpinning premise is that:

disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (preamble (e), UNCRPD, 2006).

The purpose and premise of the UNCRPD highlights the obligation of governments and communities to enable access.

The commitment to 'equal enjoyment of human rights' translates to expectations of universal access, including access to information. There are several Articles within the Convention that have relevance when reviewing policy in relation to communication about health, particularly Articles 4, 9, 21 and 25.

The principles outlined in Article 25 assert the right to healthcare access, stating that ‘persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’. Access to healthcare is underpinned by the principles in Article 9 which outlines the right to physical access to buildings and facilities or services and includes the right to ‘information and communications’ (UNCRPD, 2006).

More specifically, Article 4.1 (h) asserts that states have a responsibility to provide:

accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities (UNCRPD, 2006).

Article 21 conveys the right to both provision of information and expression of opinion:

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice (UNCRPD, 2006).

In summary, the UNCRPD states that all people have a right to varied communication formats at no additional cost, with appropriate support when required. This is to facilitate access to information, expression of opinion, decision making and access to services. The definition of communication in the UNCRPD includes various forms of text-based communication including ‘plain language’ and text adapted to enable access. Easy read and related terms are not used, but are represented by the broad categories included in the document.



As Australia has ratified the UNCRPD, the government has committed to upholding these rights and compelling non-government agencies to do so. This commitment to information access includes the right to accessible information about mental health for people with intellectual disability. Mental health policy was reviewed to determine the ways the principles of information access, expression of opinion and participation in decision making outlined in the UNCRPD are represented in policy.

#### 4.3.2 Commonwealth policy

Eighteen Commonwealth Disability, Health and Mental Health policy documents were included. An overview of all Commonwealth documents analysed is included in Table 13 (Appendix 3). Table 17 (Appendix 20) indicates whether principles associated with the right to accessible information, planning and decision making are represented in each of the Commonwealth policy documents.

Representation of accessible information: All of the Commonwealth disability policy documents recognise the rights and needs of people with disability, including the right to accessible information. The NDIS is the cornerstone of current Australian disability support policy and emphasises the right of people with disability to make decisions about their care and the need for information. Engagement of people with disability in decision making and service planning is an expectation of service, and the need for accessible information is explicit in these documents.

None of the Commonwealth health or mental health documents explicitly mention the need for easy read or plain language, however all policies recognise the value of targeted information. The *Mental Health Statement of Rights and Responsibilities 2012* states that people have a right to information in a format that they can understand, and this is

supported by the concept that diverse formats need to be made available. Similarly, the *National Aboriginal & Torres Strait Islander Suicide Prevention Strategy 2013* and *Report of the National Review of Mental Health Programs and Services 2014* state the need for various formats to enable access.

Several Commonwealth policies reinforce the value of tailored information to suit specific population groups. Both the *National Women's Health Policy 2010* and *National Male Health Policy: Building on the Strengths of Australian Males 2010* explicitly recognise the need for tailored information. The *Male Health Policy 2010* focuses on preventative health measures and requires proactive information and care. The *Women's Health Policy 2010* includes statements such as, 'Health materials and information should be developed for different groups of women' (p. 112).

All the Commonwealth mental health documents expressed a commitment to accessible information. The commitment to adaptation of information for particular groups, for example translation into languages other than English and language suitable for certain age groups, was explicit in some policy. However, adaptation for people with intellectual disability or cognitive impairment was not specifically mentioned in Commonwealth mental health policy. A detailed table of findings is available in Appendix 20.

Participation and decision making: The Commonwealth policy documents were all underpinned by the principle that people have a responsibility to make choices in relation to their care. The overarching policy documents such as the *Federal Mental Health Policy*, *Fifth National Mental Health Plan 2017* and *Mental Health Statement of Rights and Responsibilities 2012* were most explicit in the articulation of this right. While not as clear as the disability policies, the need for support to participate and make decisions was seen in

varied ways according to the particular policy's focus. The *National Male Health Policy 2010*, for example, focuses on remedying the lack of engagement of men in health-related decisions, particularly in preventative care. The *National Drug Strategy 2010-2015* recognises the value of family to support service access and decision making. The *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* has a focus on service models which can adapt to include culturally significant aspects of life such as the involvement of family and community.

Whilst all the Commonwealth policies incorporated principles that supported the right of people to make decisions about health, the *Women's Health Policy 2010* also identifies the difficulties faced by people with lower levels of literacy in decision making. This is illustrated in the statements below:

All women need to be able to make informed choices about their own health and health needs, but not all are equally equipped to participate in these decisions  
(*Women's Health Policy 2010*, p. 112)

For some women, particularly those with lower levels of education and literacy, they may experience difficulties participating in the process (*Women's Health Policy 2010*, p. 111)

All the Commonwealth documents supported the right to accessible information and participation in decision making. The principles included in the Commonwealth policy documents were supportive and inclusive of varied communication options, however the communication needs of people with intellectual disability were not explicitly stated. For further detail see Appendix 20.

#### 4.3.3 NSW policy

NSW policy related to strategic planning, directives and guidelines about direct care were analysed, with a total of thirty-one documents included (see Table 6 for inclusion criteria). A diverse selection of NSW policies was included and is listed in Appendix 3. Findings are presented in two sections:

- i) NSW legislation, strategic planning policy and related documents (Table 14, Appendix 3).
- ii) NSW policy directives and guidelines that guide service provision and day-to-day care activities in mental health services (Table 15, Appendix 3).

A summary of the way accessible information is represented in NSW Health documents is presented in Table 17, Appendix 20.

- i) NSW legislation, strategic planning policy and related documents

Representation of accessible information: The representation of communication and the right to accessible information in NSW policy mirrored the findings of the Commonwealth policy analysis. The *Disability Inclusion Action Plan 2016-19* references the UNCRPD. The principles outlined in the NSW health and mental health policies were implicitly consistent with the UNCRPD, however the UNCRPD was not referenced.

The *NSW Living Well Mental Health Policy 2014-2024* is a strategic plan for mental health in NSW. The *NSW Living Well Mental Health Policy 2014-2024* was highlighted by Dew et al. (2018) as an example of a policy which integrated the needs of people with intellectual disability appropriately. Similarly, this document clearly articulates the communication needs of various groups, including people with intellectual disability. The *NSW Living Well Mental Health Policy 2014-2024* is an example of a document that incorporates both

principles and considerations for when communicating with people with intellectual disability. The other NSW policy and action plans target the needs of specific people groups, i.e. older people, younger people and Aboriginal people. Each of these documents emphasises that access to information is important and should be implemented with various strategies. For example, the *Aboriginal Mental Health and Well Being Policy 2006-2010* highlights the importance of clear explanations and preventative information and *Safe Start Policy and Guidelines 2010* emphasises the importance of written information. The strategic planning documents, *NSW Aboriginal Health Plan 2013-2023* and *NSW State Health Plan—towards 2021* emphasise the importance of simplifying health systems to facilitate access.

Participation in decision making and planning: A commitment to consumer participation in decision making and planning was evident in all NSW strategic policy documents. The *NSW Health Disability Action Plan 2016-2019* includes clear directives about the rights of people with disability, including people with intellectual disability, to participate in all aspects of healthcare.

Very few mental health policy documents mentioned people with intellectual disability as a group with particular vulnerabilities or requirements. However, the *Women's Health Plan 2009-2011* and *Youth Health Policy 2017-2024* both recognise people with intellectual disability as a vulnerable group. These two documents also highlight the importance of support from family in communication and decision making. All the mental health documents support the inclusion of service users and their families at all levels of service provision, from individual planning through to agency governance.

There are consistent principles in the NSW strategic planning policy and related documents about the right to participation in decision making and planning, but the level of practical detail is inconsistent. All the NSW strategic policies include broad principles for practice, but the *NSW Older People's Mental Health Service Services Plan 2017-2027* has well developed planning tools and guidelines for inclusion in decision making. While the documents conveyed a varied level of detail, all of the NSW strategic policy documents reviewed had a focus on strategy and principles. The strategic and planning policy is designed to accompany policy directives and guidelines to inform practice.

ii) NSW policy directives and guidelines

The NSW policy directives and guidelines provide practical guidance to staff working in mental health services (Table 15, Appendix 3). A summary of findings about each document is located in Appendix 20.

Representation of accessible information: The NSW policy directives and guidelines were supportive of accessible communication. The importance of understandable communication is clearly stated in several documents. For example, the *Aggression, Seclusion & Restraint in Mental Health Facilities in NSW procedure 2012* requires continual staff training in therapeutic communication and highlights the varied needs of service users:

Within mental health our primary work is delivered through the medium of communication. Skill in communication across age, gender and culture is something that ought not be assumed or taken for granted but rather constantly explored and refined. (*NSW Aggression, Seclusion & Restraint procedure*, p. 42)

The importance of communication was evident throughout the documents reviewed. Some documents require the provision of interpreters, for example the *Aggression, Seclusion & Restraint in Mental Health Facilities in NSW 2012* and *Transfer of Care from Mental Health Inpatient Services 2016* policies. The *Call Handling Guidelines for Mental Health Telephone Triage Services 2012* contained detailed instruction regarding specific groups. The instruction included people with speech or hearing impairment, however no explicit mention of people who may have a cognitive impairment, comprehension difficulties or intellectual disability is included.

Although the needs of people with intellectual disability are not considered specifically, the principles outlined in the NSW policy directives and guidelines could support the use of accessible strategies such as easy read. For example, the *Engagement and Observation in Mental Health Inpatient Units 2017* focuses on risk management and the strategies do not include practical detail. There are no direct instructions about communication strategies, but the policy advises that ‘purposeful’ and ‘person centred’ communication is required when observing or monitoring. This general direction potentially leaves the practitioner with opportunity to implement strategies appropriate to people with intellectual disability as required. Similarly, the *Sexual Safety – Responsibilities and Minimum Requirements for Mental Health Services 2013* policy and guidelines highlights the need to tailor information according to the communication requirements of the service user.

Participation in decision making and planning: As the policy directives and guidelines focused on specific tasks or activities, the opportunity for participation in decision making varied according to the purpose of the document. Many of the documents have a focus on avoiding risk, and the responsibility for decisions rested with a doctor or practitioner. For

example, *Forensic Mental Health Services Policy 2012* and *Clinical Care of People Who May Be Suicidal 2016* does not incorporate a high level of participatory decision making but refers to medical practitioners, whereas policy such as *The Sexual Safety of Mental Health Consumers Guidelines 2013* and *Mental Health Triage Policy 2012* provide greater opportunity for participation in service planning and decision making.

An example of a NSW policy directive that provides comprehensive information about planning and participation is the *Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People 2012*. Consistent with the related policy, *NSW Older People’s Mental Health Plan 2017-2027*, the guideline provides comprehensive guidance to practitioners about the importance of clear, appropriate communication and inclusive, holistic planning.

All NSW policy directives and guidelines recognised the valuable role of the family/carer in decision making and support to some degree. The purpose of the policy impacted the support anticipated from the family or carer and affected the language used to describe their role. This is clearly seen in the *Forensic Mental Health Services 2012* policy, where family are in a group of ‘collateral informants’, whereas other guidelines present families as integral in providing ongoing planning and support, for example in *Transfer of Care from Mental Health Inpatient Services 2016*; *Mental Health Triage Policy 2012* and *Engagement and Observation in Mental Health Inpatient Units 2017*. Similarly, the *Chief Psychiatrist Panel Review of Complex Mental Health Treatment Plans Policy 2011* emphasised the importance of the family or carer’s awareness of the rights of people accessing mental health services.



The principles of information access and support to participate in decision making were evident in NSW policy directives, although few documents contained detail about communication strategies. The policies related to *NSW Older People's Mental Health Services Service Plan 2017-2027* provided an example of a comprehensive suite of principles, strategies and planning tools. However, the importance of accessible information and the needs of different people groups was not articulated consistently across policy directives. For example, the *Call Handling Guidelines for Mental Health Telephone Triage 2012* and *Mental Health Triage Policy 2012* advise that information needs to be tailored to meet the needs of specific groups, such as people with speech and hearing impairments or cultural or language needs. This list of groups to consider does not include people with cognitive impairment or limited verbal skills. Some documents mentioned intellectual disability, as presented in Appendix 20, however this mention was to generally refer to the Memorandum of Understanding (MOU) between government health and disability departments, rather than to recognise particular needs or vulnerabilities. The needs of people with limited or low literacy were absent from the considerations included in the documents.

#### 4.3.4 Health agency (Local Health District) documents

Seventeen Agency-specific Local Health Districts (LHDs) policy documents were reviewed. All three participating health Agencies (these are described in Chapter 3) referenced the NSW Health policy and guidelines as the framework for their practice. Documentation developed by LHDs to support NSW policy and guidelines has been included and is described in Table 16 (Appendix 3). The documentation available across the three Agencies was inconsistent as

access to Agency-specific policy documents varied (see methodological limitations in Section 3.5).

Representation of accessible information: All of the LHD policies stated that access to information for service users was important. Most recognised the need for culturally and linguistically appropriate communication. They had varying levels of detail and expectation of information accessibility. The policies from Agency 1 and 2 were similar as they provided support for principles of access with limited strategy, whereas Agency 3 provided a commitment to principles along with strategies to address various communication issues, including those appropriate for people with intellectual disability.

Policies from Agency 1 and 2 contained a commitment to principles of information access but do not provide strategies to enable access for people with intellectual disability. None of the documents provided from Agency 1 mentioned the needs of people with intellectual disability or cognitive impairment and therefore do not advise specific communication options. While two of the policies at Agency 2 recognise the vulnerabilities of people with intellectual disability in the policy area, there are no specific guidelines regarding communication for this group. The instruction provided in policy for staff reinforces the importance of understandable information, but does not provide specific strategies to use when working with people with intellectual disability. For example, *Document 2.4 Patient Leave From Acute Care Policy* states that 'Clear, simply written instructions and information about agreed responsibilities must be given to the patient/carer when overnight leave is taken'.

Another example of this commitment to access is the emphasis that *Document 2.8 Telephone Support* places on the need for tailored communication for specific groups.

However, no specific instruction for people who may have difficulty comprehending or processing information is provided. Similarly, *Document 1.3 Communication* offers guidance for staff deciding whether to display information from external providers in hospital facilities. This document reflects a commitment to providing quality information, but has a focus on content rather than accessibility or readability.

In contrast to Agency 1 and 2, policy from Agency 3 clearly states the need for accessible information for people with intellectual disability and other people with limited literacy. Agency 3 policy mentions intellectual disability in only one of the five policies, yet a commitment to accessible information is evident in all policy analysed. *Document 3.3* outlines the potential needs of people with intellectual disability and co-occurring mental ill-health in the hospital setting, including accessible communication. The link between behaviour and communication is noted. This document highlights the need to tailor information and includes consideration of providing information via tailored, non-text-based means. The concept of establishing a communication channel conveys the two-way flow of information. The document offers many options for communication and highlights the need for simple language and visual supports.

The terms 'easy read', 'easy to read', 'plain English' and 'easy English' are not included in *Document 3.3*. However, these terms are used in *Document 3.2* about fact sheet development and in *Document 3.5* about rights and responsibilities, but without specific reference to people with intellectual disability. The policies available from Agency 3 all reflect a commitment to principles of accessible communication as well as specific examples of strategies to enable access to information for various groups.

Participation and decision making and planning: All of the LHD policy recognised the importance of participation in decision making where possible and the valuable role of the family or carer to support this process. While the value of participation is apparent across the LHD policy, the tension between participation and risk management is evident throughout these documents.

Management of risk was a theme present in several of the LHD policies and this is not unexpected due to the type of services provided (see Table 17, Appendix 20 for detail). The specific focus of the directive or guideline impacts the opportunities for service user participation in decision making, and the tone of instruction given to staff reflects this. For example, the detailed instruction and conversation suggestions included in *Document 1.1* about discharge processes and in *Document 1.2* about community visits relate to service timeframe, safety and appropriate levels of support. *Document 1.1* states that 'Patient and carer participation should be encouraged early and throughout'. *Document 1.1* also stipulates that 'An individual care plan which is collaborative, transparent and clearly understood by the patient' is required.

At a service level, although people with intellectual disability are not mentioned as a specific group, the importance of participation is outlined in documents such as *Document 1.4* and *Document 2.7* when outlining committee representation procedures. These documents also recommend participation and representation from the family or carer. The policy documents conveyed an understanding that people using mental health services may require representation and support from family members. This is seen in the level of consultation recommended across the policy analysed. While explicit information about the role the family or carer plays in supporting communication, the integral role of families/

carers in access and in information transfer and decision making is evident throughout LHD policy documents.

## 4.4 Summary of policy analysis findings

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This policy analysis showed that there is limited representation of the communication needs of people with intellectual disability in mental health policy. This finding is somewhat unsurprising given the experiences of complexity in past practices and in more recent history (described in Chapter 1). The results of this policy analysis reinforce Dew et al.'s (2018) findings about the broader representation of people with intellectual disability in mental health policy.

At the beginning of this review two research questions were posed:

*How does the current positioning of easy read in policy enable information access within mental health services?*

*How are the rights relating to information access outlined in the UNCRPD represented in policy?*

To answer these questions from the analysis of the Commonwealth, state and LHD policies it is useful to consider findings in three themes. The themes of easy read, information access, and communication strategies for people with intellectual disability are each explored.

When examining the question of how easy read was positioned in policy, the most immediate observation was that the term 'easy read' was rarely used. There was limited use of the term 'easy read' in disability-related documents. In health and mental health policy

the term 'easy read' appeared in relation to groups other than people with intellectual disability. There did not appear to be a consistently used alternative term used in place of 'easy read' to describe written information tailored for people with an intellectual disability. This absence is significant, and in keeping with the lack of consistency in definitions found in the broader research context presented in Chapter 2.

The policy documents reflected a commitment to the values articulated in the UNCRPD and many policies recognised the need for accessible communication. Disability policy articulated the needs of people with intellectual disability, and the *NDIS Act 2013* and related policy supported tailored communication to meet individual need. This consistency was also evident in the strategic Commonwealth and NSW Health and Mental Health strategic planning documents. While none of the NSW or LHD policy discouraged the use of tailored information, some documents had more explicit instructions regarding accessible communication than others. There was a commitment to the principle of information access in policy, however there was a lack of uniformity in the inclusion of detailed strategy and instruction about communication across agencies.

The findings reflected that mainstream mental health communication was often reliant on text, with minimal consideration of communicating to people with limited literacy or who had difficulty understanding (as outlined in Chapter 2). The use of communication strategies such as easy read or simplified text documents for people with intellectual disability was supported by broad principles in mental health policy. However, it was not outlined in recommendations or guidelines for practice at any level of mental health policy analysed.

The exception to this finding in the review was Agency 3 LHD-level documentation. Agency 3 was a specialised health service for people with intellectual disability and this specialist

orientation was reflected in their policy. The guidelines and policy documents from Agency 3 incorporated various inclusive strategies suitable for service users and their family or carer. Agency 3 staff reflections about the impact of policy on their practice is explored further in Chapter 5.

The lack of uniformity and limited information about communicating with people with intellectual disability reflected a broader trend. There was limited instruction for practitioners about the information needs of people with intellectual disability or limited literacy, although some LHD and NSW policy documents provided specific instruction about communication strategies for other groups. The *NSW Mental Health Triage Policy 2012*, for example, provided detailed instruction about communication with many identified groups. This included people with sight impairments, hearing impairments and CALD communities, however the needs of people with intellectual disability or limited literacy were not included. The absence of communication strategies tailored for people with intellectual disability in policy reflected the problematic service landscape and limited recognition or inclusion of people with intellectual disability by mental health services historically (as discussed in Chapter 2).

The limited consideration of the communication needs of people with intellectual disability in mental health policy is perhaps symptomatic of the broader under-recognition of the mental health needs of people with intellectual disability identified in the literature. Disability policy clearly articulates the value of accessible information for people with intellectual disability, in contrast to mental health policy which was inconsistent in the level of instruction provided. There was greater congruence between overarching rights and instruction about making information available to people with intellectual disability in

disability policy than in mental health documentation. This disparity between disability and mental health policies further underlines the impact of the historic division between services for people with intellectual disability and people experiencing mental ill-health.

Most mental health policies did not identify people with intellectual disability as a service user group and this invisibility reflected continued under-recognition of mental health issues in people with intellectual disability. Ideally, the recognition of people with intellectual disability as service users with particular needs would underpin the systematic inclusion of and commitment to suitable communication strategies. Several documents were supportive of individualised, tailored communication without identifying people with intellectual disability as a service user group. The impact of this lack of specificity on practice is worth exploring as many of the policies incorporated the right to accessible information and the importance of tailoring communication without articulating the strategies required to do so.

#### 4.4.1 From policy to practice

This analysis has outlined what is articulated in policy about access to information formally or 'on the books'. Questions then come to the fore about the experiences of people 'on the streets' who use or work in services guided by the policy included in this review (Turnbull & Stowe, 2017, p. 27). The lack of specific guidance about communication strategies for people with intellectual disability raises questions worthy of consideration in this research, such as:

With limited specific guidance in policy, how do staff working day-to-day gain information about working with people with intellectual disability? Is the current inconsistency in the level of specificity an issue for practice?



Additionally, another more specific issue to consider is whether the term 'easy read' is in use at a practice level and if not, whether there is another term commonly used to describe simplified text documents.

The questions raised in the policy analysis informed the interviews with staff participants. Staff interviews encompassed the connections between policy, agency culture and accessible communication. Chapters 5-7 present the interview findings in relation to the activities of accessing, understanding, appraising and applying information (Sørensen et al., 2012). Findings about the connection between policy and staff practices are evident throughout the research findings and are most pertinent to Chapter 5. Chapter 5 has a focus on access to information, particularly the responsibility of agencies to facilitate access and provide inclusive communication options.

## CHAPTER 5: ACCESS TO INFORMATION

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This is the first of three findings chapters focused on data from interviews and resource mapping. The concepts of accessing, understanding, appraising and applying information described by Sørensen et al.(2012) frame these chapters. According to Sørensen et al. (2012), access to information is about people being able to gather, locate or find the health information they need. The concept of *access* relates to the way people, and those who support them, navigate systems to find information. In addition to personal and social considerations, Sørensen et al. recognise the impact of what they call ‘agency readability’, or agency accessibility, on the experiences of people accessing health information (Sørensen et al, 2012, p. 10). This chapter builds on the findings of the policy analysis to discover how health Agencies facilitated access to information for service users with intellectual disability. The concepts explored in this chapter relate most directly to research questions 1 and 2:

*How does the current positioning of easy read in policy enable information access within mental health services?*

*How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?*

Agency accessibility is an integral concept in this research, particularly the ways in which Agencies make information available to people with intellectual disability.

Lara was not a service user at any of the participating mental health services. The story of Lara's experience introduces the concept of access.

## LARA

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Lara<sup>1</sup> was a woman in her 20s who had support from Fran for many years. Fran was a paid respite worker who knew Lara's family well and saw Lara at least once a week to accompany her to meetings and recreational activities. Lara travelled with support and worked part-time in supported employment. Lara was very close to Fran and also had a supportive family. Lara's family could read English and understand most things, but did not speak English at home. Lara was not a user of mental health services, but her story had relevance for mental health settings.

Lara told me about her recent hospital admissions, specialist appointments and allergies. Lara's mother always accompanied Lara to medical appointments and Lara referred to her mother as the decision maker when we discussed her appointments at the GP. When asked about health-related information, Lara said: 'He [the doctor] just talks to my mum and writes things down for her'. When asked about how she prefers the doctor to communicate information, Lara said: 'That's the doctor's job not mine'. Lara was reliant on her mum to take her to appointments and to provide information after appointments.

An event that occurred just over a year before still troubled Lara's support worker Fran. Fran went to Lara's home at the time of her usual respite shift and found that Lara was very unwell and shaky on her feet. The family called an ambulance and asked Fran to accompany

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<sup>1</sup> Pseudonyms used for all names in the findings chapters

them to hospital with Lara. The emergency department staff assessed Lara. Lara was moved to a room and Fran stayed with her. Fran overheard a conversation between the doctors who were with Lara's mother. Fran was distressed at the lack of interaction with Lara and was concerned that doctors did not explain the diagnosis to the family or to Lara. Fran said:

‘– but they did not explain nothing and I could hear like ... she has got a little stroke and the mother understands nothing but not on paper just like this and after I said to the mother did you hear what they said? and she didn't ... not at all’.

Interviewer: So you didn't think that they spoke to Lara at all?

Fran: No not at all ... I was there the whole time – the main thing is something really ... I think it's good for her to know things on paper for her especially because you know how good she remembers things – she is very clever. For mum and dad, for me it's OK but for her – she knows everythings’.

The hospital staff did not speak directly to Lara about their concerns or a potential diagnosis during her hospital stay. At the time of the interview, Fran was still unsure whether Lara or her family knew that the doctors suspected that she had experienced a stroke.

Fran explained that Lara kept all information about health and appointments in a folder. Lara revisited the health information from appointments to discuss, remember and consider. Fran felt strongly that easy read information would have been beneficial for Lara to alleviate her anxieties and to enable her to discuss her medical situation with others when in hospital. Fran and Lara used easy read to discuss other activities and plans and found it very effective. They said that easy read about mental health would be useful for Lara if she ever needed to use mental health services or to learn about her mental health.

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Applying the integrated health literacy framework to Lara's experience, she had access to healthcare and potentially to health information. Lara had contact with service providers who had information about her condition, and had support from her family and familiar paid carer. These factors appeared to create an environment that could support Lara to gain the information she needed. Lara's experience raises many questions about the role of agencies in providing access to information that are relevant to this research, such as, Why did Lara miss out on receiving this information? What could have enabled access? Was easy read information available? Additionally, how could Lara's experience apply to a mental health setting?

This chapter incorporates the experiences of people with intellectual disability, as well as staff working within Agencies governed by the policies that were analysed in Chapter 4. Agency practices are a key focus of this chapter. First, the accessible information resources designed for people with intellectual disability available at each Agency are summarised. Then, the factors that impacted information access are examined. The last section of the chapter explores how Agencies supported staff to facilitate access to information.

## 5.1 Availability of accessible information at the participating Agencies

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Establishing whether easy read, or other accessible information, was available at the participating Agencies is a first step to exploring how it was used. This section summarises the accessible communication resources designed for people with intellectual disability available at the four participating Agencies. The summary is intended to be read in

conjunction with the Agency information provided in Chapter 3, as a foundation for the interview data analysis that follows.

Providing health information was a core task of each of the Agencies involved in this study. The Agencies had different purposes, models of operation and varied availability of accessible communication resources. At the community health services, accessing information often involved the task of locating information at a service shopfront or via a flyer, whereas at hospitals, access to information was often dependent upon admission and was provided by staff in a face-to-face interaction. At Agency 4, people with intellectual disability contacted staff for information about health and about many other subject areas. There was variation in how much accessible information was available at each agency. Agency 4 had a range of accessible information, whereas the health Agencies (Agencies 1-3) had limited availability. None of the health Agencies (1-3) had agency-wide standards for making communication accessible communication. Most staff at the health Agencies were unfamiliar with the term 'easy read' and no standardised list or directory of accessible information was available from NSW Health or at any Agency. The accessible information available at each Agency is mapped in 5.1.1, after which staff reflections about information access at each Agency are summarised in 5.1.2.

#### 5.1.1 Mapping accessible communication resources

The easy read resources available at each Agency were mapped to provide a summary of the resources available (see Methods, in Chapter 3). A search was conducted online, prior to the staff interviews, to locate any libraries or directories of accessible information available to health staff. The NSW Department of Health and Local Health District websites were searched, and no comprehensive directory of accessible health resources or mental health

information was available. Some easy read resources and guidance for staff supporting people with intellectual disability accessing health services were located, from disability agencies such as SCOPE Victoria and NSW CID, the Agency for Clinical Innovation (NSW Health) and the Department of Developmental and Neuropsychiatry (3DN) website. A manager at Agency 3 identified some of these resources as relevant and valuable, but said that staff did not use them. As these resources were not used at the participating Agencies, they were not included in the summary table (Table 10).

To facilitate the resource mapping, during the interviews staff were asked to describe any adapted or modified documents tailored for use with people with intellectual disability available at their Agency (see the interview schedule in Appendix 8). Some staff brought samples of the accessible documents they used to the interview as an example. The resources mapped included easy read, or other paper-based accessible information designed to make information easier for people with intellectual disability to understand. Table 10 summarises the accessible information available at each Agency and is designed to provide a reference point for the findings which follow.

**Table 10: Accessible document availability by agency**

		Agency 1 <i>Public mental health</i>	Agency 2 <i>Public mental health</i>	Agency 3 <i>Specialised Intellectual Disability health</i>	Agency 4 <i>Intellectual Disability advocacy</i>
Number of participants		8	13	16	12
Document type	Agency policy				
	Agency forms				
	Healthcare - generic				
	Healthcare - individual				
	Disease prevention - generic				
	Disease prevention - individual				
	Health promotion - generic				

Key:	white	staff were unaware of this resource being used or available at their Agency
	Grey	at least one staff member had used or seen this resource used at their Agency
	Black	over half of staff interviewed indicated that they had seen or used this resource

### 5.1.2 Staff reflections about the availability of accessible information

#### Agency 1

Agency 1 was a publicly funded mental health service. Staff did not use accessible information routinely, had only used easy read information with specific patients, and did not have any ready-made accessible information available. Staff spoke about some



instances where they had seen accessible or easy read-style information used at their Agency. They sometimes used easy read to convey routines or individual behaviour management strategies, as reflected in Table 10. Agency 1 staff occasionally developed accessible resources for this purpose, but accessible information was most often supplied by the support services, family or carers of the person with intellectual disability. A staff member recognised that information access for people with intellectual disability was inadequate in their Agency and they were open to change, stating: 'I don't think we are doing a lot but there is a lot of goodwill'.

When working with people with intellectual disability to discuss mental health issues or services, staff at Agency 1 used the standard agency documentation. Staff referred to an example of an admission kit that each patient received. These documents were not available in an easy read or accessible format. Several staff indicated that the information given to service users at admission was difficult to understand.

The views and experiences of staff interviewed at Agency 1 reflected that the agency was in a state of transition. Many staff at Agency 1 were accustomed to services for people with intellectual disability being provided at a separate location, and the adjustment to a more inclusive model was still underway (see Agency 1 description in Chapter 3). Most staff had minimal awareness of the needs of people with intellectual disability or the communication resources available to meet these needs, apart from two staff working in a newly established specialised intellectual disability mental health support team. The specialised staff had great insight into communication with people with intellectual disability and were enthusiastic to create new ways of working and communicating. A member of the specialist

team was eager to develop easy read resources and commented, 'I think it would be essential to use but I do not see it readily available – so that's a major barrier'.

#### Agency 2

Agency 2 was a publicly funded mental health service. Some Agency 2 staff had experience in developing individualised information with people with intellectual disability, but no information was routinely available in accessible formats. Agency 2 primarily developed and used easy read for individual patients to convey routines or behaviour plans. Sometimes the intellectual disability mental health clinical coordinator at Agency 2 developed individualised resources about specific service or health issues (see Table 10). One staff member noted that some staff had past employment experiences which equipped them with knowledge about the communication needs of people with intellectual disability. These experienced staff supported their teams to make communication resources for people with intellectual disability. This cooperation was reflected in a quote from a staff member working in an inpatient setting:

We're very lucky that we have a number of staff that have actually worked in intellectually [sic] disability backgrounds and so I know for a fact that we developed communication tools.

Agency 2 had a specialist staff member available to support communication with people with intellectual disability. Their role included creating communication resources for patients and supporting staff. Staff skill development was a central responsibility of the disability support role. However, the specialised staff member was responsible for support to numerous staff at varying locations and had little time for staff development activities after attending to urgent individual client needs.

Some simplified information was available (for example, brochures used to convey information to dementia patients, simplified information for teenagers about mental health issues). However, the simplified materials were not tailored for people with intellectual disability. A staff member at Agency 2 commented that they lacked appropriate communication tools for people with intellectual disability:

We do that [provide information] as much as we can verbally, but often we don't have those information [written documents] to support that ... we don't have that.

Staff did not always feel that they were able to meet the communication needs of people with intellectual disability, but were aware of their responsibility to engage all people in decisions about their care. Many Agency 2 staff said that their managers supported them to communicate in a personalised, tailored way to suit people who used their service, but the staff did not always have the skill or resources to communicate in this way. Most staff at Agency 2 did not regularly use easy read, but had seen it, and were enthusiastic about the potential of easy read as a communication strategy.

### Agency 3

Agency 3 was a specialised intellectual disability service for children and younger people, and included a mental health team. Staff at Agency 3 actively sought to make information accessible to people with intellectual disability and their families via multiple modes including easy read documents. A simple map with easy read directions accompanied by pictures of how to find the service was routinely sent to families attending the clinic for the first time. The map and directions were among several resources described by staff. Agency 3 staff used many accessible information resources, and this is reflected in the resources mapped. Staff did not use the term 'easy read', but used many resources that would fit the

definition of easy read. Findings about the availability of accessible information have been summarised in Table 10.

Agency 3 staff worked across numerous disciplines and many staff used tailored easy read resources for therapeutic work with individuals. For example, psychologists, dieticians and exercise physiologists used tailored documents to enable service users to chart progress or maintain routines. Staff produced tailored documents when required, particularly for service users who were anxious about their visit. The standard easy read documents that Agency 3 used were often about staff roles, directions to the agency and hospital processes. Most staff at Agency 3 were committed to flexible communication and to providing information in formats to suit service users. One staff member involved in intake processes commented:

The way we are set up we haven't set up any barriers – anybody can come if they are struggling and if they are not best suited here we can guide them.

A staff member in a management role at Agency 3 was aware that resources were available to support staff to create accessible information, but that they were not widely used at the Agency or more broadly in the hospital. The manager described two accessible NSW Health resources that were available but not used at Agency 3. *Show more say less* is an online resource which includes e-learning modules and resources such as social stories to facilitate discussion and explain medical procedures when supporting a person with intellectual disability to access health services (Agency for Clinical Innovation, 2020a). *The Essentials* is a package of information which sets out 10 principles when working with people with intellectual disability (Agency for Clinical Innovation, 2017). These resources were not included in the documents mapped (Table 10) as they were not used by staff at Agency 3.

## Agency 4

Agency 4 was an intellectual disability advocacy service. Agency 4 was actively engaged in creating, and advocating for the use of easy read, and staff brought numerous examples of easy read documents to interviews. These documents included letters tailored for individual use, brochures about rights, presentations about health, meeting agendas, and the agency's annual report. Table 10 reflects the varied array of easy read documents available at Agency 4 and Appendix 21 has information about how easy read was produced and used. People with intellectual disability were actively involved in Agency governance and advocacy activities in paid and unpaid roles and easy read versions of all Agency documentation was available. Staff at Agency 4 said that they used easy read in various contexts to provide accessible information to people with intellectual disability (see Appendix 21). Agency 4 participants said that easy read was difficult to create, but very worthwhile.

Agency 4 conducted training in easy read development and had developed a guide for production of easy read. Agency 4 created easy read for other organisations such as disability agency policy, complaints brochures, local government information, contracts and service agreements (Appendix 21). One Agency 4 staff member commented about easy read in other agencies: 'it's certainly on people's radar but nobody is really doing it well'.

Agency 4 had a guide for staff producing easy read which outlined the key features, provided a framework and emphasised the need to tailor for individual differences. Since the interviews took place, Agency 4 has developed a comprehensive resource to facilitate communication at medical appointments. As this was still in development, participants had not used the resource and so did not comment on its utility.

Mapping accessible information and staff reflections about information access

demonstrated the varied availability and use of accessible or easy read resources at each of the Agencies. At some Agencies staff had little understanding of the communication needs of people with intellectual disability, they had few resources, and they described a culture where accessible information was an add-on or extra to include if time and skill allowed. By contrast, at other Agencies there were varied resources and a rich culture of inclusion.

## 5.2 Making information accessible

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The availability of easy read was crucial, but there were many other factors raised in the interviews that influenced whether easy read or accessible information was available to people with intellectual disability. Many participants, both staff and service users, highlighted how difficult it was for people with intellectual disability to access the health information they needed. Lara's hospital visit, described at the start of this chapter, was one example of several shared by people with intellectual disability who had encountered difficulty accessing health information. The experiences of mental health agency staff who provided information echoed these findings. To understand more about how easy read is used it is helpful to gain an insight into the barriers and supports to information access at mental health Agencies.

Many staff working at the mental health Agencies were aware of their responsibility to meet varied information and communication needs, but felt that their services failed to provide adequate information to people with intellectual disability. They identified that service users often faced many personal or social barriers to information access that their Agency had an obligation to accommodate. Factors such as mental well-being, level of family support, and

service users' knowledge of the service all impacted how service users accessed information. The participants identified some common agency features that impacted health agency capacity to support varied individual needs – both positively and negatively. They identified four key factors that impacted accessing information across the Agency types: service provider relationships, time, the option to involve family or carer, and the service environment.

### 5.2.1 Service provider relationships

Findings from all the participant groups highlighted the potential impact of the relationship between staff and people with intellectual disability on opportunities to access or locate information. People with intellectual disability did not access any of the participating mental health Agencies, but were all experienced in seeking out health information. All of the people with intellectual disability identified that they regarded health agencies to be a vital source of information.

Several participants with intellectual disability said that they were reluctant to approach or return to services where they felt disrespected, unwelcome or unable to ask questions or clarify information. Participants with intellectual disability identified the importance of respectful interactions with staff in public areas such as reception or intake desks, as well as during appointments. For example, one participant with intellectual disability said that the attitude of his doctor was central to his decision about which general practitioner to see:

I wouldn't want to see a doctor who is like 'oh no not him again'... if I went to a doctor and the doctor wasn't very happy [to see me] I would be like, 'See ya, I'm finding another doctor'.

At participating agencies frontline staff and health practitioners were a key source of health information. Staff also recognised the impact of the relationship with service users and several spoke about the importance of rapport building to support effective communication. A staff member providing specialist intellectual disability support at a mental health Agency expressed concern that some staff lacked confidence to initiate relationships with people with intellectual disability, which impacted their capacity to build rapport. She saw that building rapport was essential to effective communication:

First of all, you need to have a rapport with that person because you need to build a relationship with that person in order to give them information that they will respect and use, or at least, listen to.

The participants with intellectual disability valued respectful relationships to negotiate the way that family or carers were included in accessing information. Several participants with intellectual disability emphasised the importance of finding a medical practitioner who discussed the role of family or carer directly with them. A participant with intellectual disability commented that she was often overlooked by medical practitioners when she attended appointments with her family or carer. She said, 'Doctors need to be able to communicate with someone with a disability no matter what their disability is'.

Staff and participants with intellectual disability highlighted that establishing a consistent, ongoing relationship to facilitate information access was ideal. One participant with intellectual disability said, 'I want someone who understands me ... I have been struggling to find a doctor ... I haven't had this for a long time'. Some participants with intellectual disability said that having the same health practitioner made it easier to exchange information. Similarly, others said that they valued seeing a doctor who they had known for



a long time, and highlighted the difficulties associated with medical centres that allocate one of multiple practitioners. For many participants, opportunities for service users and providers to establish consistent, respectful relationships were closely linked to whether Agency processes fostered, or hindered relationship building and effective communication.

#### 5.2.2. Time and flexibility

The impact of limited time and Agency pressures on interactions between staff and service users was evident throughout the interviews. Several staff articulated that their ability to relate in respectful ways was often dependent on factors beyond personality or individual demeanour. Some staff said that the pressure of Agency expectations significantly impacted their interactions. One manager commented, 'At a busy clinic with performance targets it can be difficult to be friendly running a very tight ship'. Staff participants often attributed difficulties in finding or providing accessible information to agency pressures or structures. Similarly, most people with intellectual disability interviewed found the time pressure in many health services restricted their opportunity to gather information. A participant with intellectual disability commented:

Doctors are pretty well rushed and I know that for a fact ... if you have a disability you should be able to set up a longer consultation ... so you are both well informed about each other.

Likewise, staff at Agencies 1 and 2 said that their service environment hampered their efforts to support people with intellectual disability to find or locate information. Several staff said that reactive, time-limited service models did not foster or support effective communication. Many staff described an environment characterised by a lack of flexibility, time limitations, pressures of other administrative duties or patients to see. Many staff

working in inpatient settings indicated that at their services, staff often felt rushed and had limited time to focus on individual communication needs. Several staff emphasised the need for time to develop a relationship to foster communication. A specialist intellectual disability mental health staff member stated:

The people [with] intellectual disability have told me that it often is about taking time with them ... that it even will take folks longer potentially to feel safe. So, take – you might be used to spending three sessions getting to know someone, take eight.

The perception that community-based mental health services had greater flexibility and a focus which was more conducive to effective communication than inpatient services was common among staff. For example, at a community-based specialist intellectual disability service, staff said they were able to tailor the time, location and number of appointments appropriate to meet family needs. A staff member said, 'We have flexibility to do whatever we need to do to give best chance of implementation'. Having a flexible service structure also allowed staff to choose the modes of communication which were most appropriate for the service user, and this often involved including families or carers in appointments.

### 5.2.3 Including families or carers

Staff and people with intellectual disability identified that the support of families or carers was valuable, but that these relationships could be complex to navigate. Most people with intellectual disability interviewed attended healthcare visits with family members/carers. They said family members/carers often gave logistical support (such as transport or payment), facilitated communication (verbally or with resources such as easy read), or gave emotional support. Some participants, both people with intellectual disability and staff, said that relationships with family members sometimes made information and service access

difficult. For example, one participant with intellectual disability found it difficult when his mother had strong opinions about health choices which she aired during appointments. Her opinions made it difficult for him to gather information about health subjects pertinent to his needs.

Many of the people with intellectual disability, and several staff, emphasised the need to negotiate family or carer involvement at the commencement of service. Others highlighted the importance of re-negotiating this involvement throughout the service provision. Several people with intellectual disability reinforced the need to regularly check in with them about their family or carer's support role. Many people with intellectual disability preferred different support according to the appointment type, and some people said that they no longer require this support with the GP or other familiar health practitioners. For example, a participant with intellectual disability stated, 'I just do it all on my own – I don't like to worry anyone'.

The experiences of participants with intellectual disability varied. Some required minimal support from family or carer to find health information and make decisions, while other people were dependent on family for all aspects of decision making. Gail was the only parent interviewed and her experience illustrated the key role of families or carers for some people with intellectual disability. Gail attended appointments, communicated on her son's behalf and sought to interpret his behaviours to assist doctors to determine a diagnosis and medication for his mental health concerns. She stated, 'You know you know your kid, you just know'. Gail spoke about the responsibility she felt as the parent of a young man with intellectual disability, who used limited verbal communication, and experienced mental ill-

health. Gail said that she felt uncomfortable at times in accessing information to make decisions about medication and side effects on behalf of her son.

Staff at all Agencies recognised the value of family to support access to information before, during and after appointments. One practitioner saw families had a valuable role as 'historians and advocates'. All staff said that families were a valuable source of information to plan treatment and facilitate communication when the patient being admitted to the service was experiencing a significant episode of mental ill-health. Several staff participants said that people with intellectual disability without family support were particularly at risk of not accessing preventative care and being less aware of treatment or service options.

Staff also recognised that service users and families or carers they worked with often faced multiple obstacles to service and information access which agencies needed to consider.

Staff at Agency 3, for example, regularly saw people who were under financial stress, many had limited literacy and experienced significant family demands with little social support.

These factors impacted the capacity of the family or carer and Agency staff to support the person with intellectual disability to find both information and services.

The staff noted that the stresses and complexities of life and family relationships for people accessing information reinforced the benefits of making information that is easy to understand available to people with intellectual disability and their families. Despite the complexities of family relationships, many staff and service user participants identified family as a supportive factor for people with intellectual disability finding information. This is discussed further in later chapters about understanding, appraising and applying information.

#### 5.2.4 Service environment

Most of the people with intellectual disability expressed that they were often apprehensive about attending medical appointments and accessing health services. This finding was unsurprising as reluctance to engage with health agencies was evident in the literature (Chapters 1 and 2). The participants with intellectual disability were not users of the mental health Agencies, but many of them expressed anxiety about health service environments, for example about attending GP appointments or hospital stays. They said that their anxiety about the health service context had impacted their access to information and also limited their opportunities to make decisions (see Chapter 7 for further discussion). Staff perspectives elaborated on the impact of the health service environment on the willingness of people with intellectual disability to interact with health services in order to find information.

Staff at the mental health Agencies said that underlying anxiety associated with health service use experienced by many service users with intellectual disability was compounded by the mental health service setting. In a mental health setting staff said that service users were at times fearful due to their current or prior experience of mental ill-health and the service environment compounded these issues. These findings reflected the trauma-informed care literature (Chapter 1). Several staff highlighted the inpatient environment as being particularly problematic for enabling access to information for people with intellectual disability. For example, a specialist intellectual disability worker at a mental health Agency commented:

Well, it is a – I think in inpatient, it is very crisis-oriented, like an emergency department. I mean, there's high stress all the time. You have people in distress. So, other – even at other hospital inpatient units, there will be some quietness and peace, and that is not what you will see if you visit the inpatient unit. It's people screaming. It's people walking around, pacing, feeling stressed.

Staff recognised that the high levels of anxiety in the inpatient setting impacted both the immediate capacity of people to find the information they required, as well as to remember information discussed if they required it at a later date. The impact of the service environment was most evident in staff reflections about their legal responsibility to provide access to information at the time of admission. Many staff at Agencies 1 and 2 were concerned that their agencies did not consistently provide accessible admission information for people with intellectual disability. Staff recognised both the systemic issues preventing staff being able to spend the time they required to provide information to service users as well as their attitude, limited skills and confidence to do this. A manager at a generalist mental health service commented:

I don't think we do it well. We provide the brochure but we don't always accompany it with the discussion and opportunity. I think it often comes down to people's [staff's] time, it's people's [staff] confidence around it, people's time and then people's capacity and the way that they see the world, I guess.

Many staff did not think that people with intellectual disability had adequate access to information at their Agencies. Practices between staff varied and opportunities for people with intellectual disability to access information were not always available. Health staff

identified that they needed greater Agency support to enable them to consistently provide access to information for people with intellectual disability.

## 5.3 Supporting staff to facilitate access to information

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Health staff were aware of the need to provide accessible information to service users, but not all staff were confident to do this when working with people with intellectual disability. Many staff struggled with the challenges to communication in the mental health service environment (explored in Section 5.2). Staff attributed their limited use of accessible information to a lack of time, skill, confidence, limited availability of accessible information resources or a combination of these factors. Most health staff thought that they needed greater agency support to facilitate consistent access to information for people with intellectual disability. Many said providing accessible information for people with intellectual disability was dependent on individual staff members' professional, or moral commitment rather than an Agency obligation.

This section analyses findings about how Agencies can better support staff to provide access to information for service users with intellectual disability. Staff identified that they need more opportunities for collaboration and training, access to appropriate communication resources, as well as policy and procedures to endorse these strategies.

### 5.3.1 Collaboration and staff training

The staff participants' level of confidence to communicate with people with intellectual disability reflected the variation in service focus of the participating Agencies (see Section 5.1). Staff at mental health Agencies said that their generalist medical and nursing training

did not equip them well to facilitate access to information when working with people with intellectual disability. The following quote from a specialist medical practitioner about communicating with people with intellectual disability exemplifies this finding:

So lots of different ways that perhaps approaching relationship with such impaired patients. And certainly something I feel completely unskilled as a consultant so I very much allow other people to advise and take the lead on those particular individuals.

Many generalist mental health staff said that people with intellectual disability were outside their area of knowledge or expertise. A manager of a generalist inpatient mental health service commented, 'I don't think we have the expertise – to be totally honest ... we're not really equipped'.

When discussing training, staff at Agencies 1 and 2 said that the main source of education about communication and enabling access to information was in recovery-oriented care training. The recovery-oriented framework incorporated strategies to meet the needs of people with varying communication needs, but did not contain detail to support them to meet the needs of people with intellectual disability. The framework incorporated involvement of service users and their families in decisions and planning and many of the principles mirrored those of the person-centred care models in disability practices. Staff said that the principles were supportive, but their training did not include content about communication resources or options suitable for people with intellectual disability. An experienced staff member at a generalist mental health Agency commented:

I mean we have a recovery framework and so that encompasses everybody really and that's saying – getting to know the person, what are



their recovery goals, that kind of thing, but probably not so much. They're not tailored to some people with an intellectual disability.

Staff at all Agencies highlighted the importance of a supportive team to enable them to facilitate access to information. Staff provided examples of when their team had supported them to learn about, find, and/or create accessible communication resources. Many staff presented scenarios to illustrate when they had collaborated to meet the needs of people with intellectual disability, yet they reported they felt ill-equipped. A staff member working in allied health at a generalist inpatient service commented:

We do try our best and, of course, nursing staff aren't trained with intellectual disability particularly because mental health is the focus but they're very good too, the nursing staff.

Support from colleagues at their workplace to assist in understanding and meeting the communication needs of service users with intellectual disability was valued by staff from all Agencies. Agency 3 staff were all experienced in working with people with intellectual disability and valued the mentoring and expertise of colleagues for skill development. Staff from Agency 3 had access to speech pathology staff, but consultation was not always possible. Several staff at Agency 3 said that they valued the collaborative nature of their team as it enabled them to learn from one another in shared appointments and informal consultations to facilitate access for service users who required strategies that they were unfamiliar with. One Agency 3 staff member commented, '...everyone genuinely cares and is ready to drop everything to support each other.'

At Agencies 1 and 2, most staff had limited experience working with people with intellectual disability and valued the input of others to facilitate access to information. Staff presented

several examples of the ways that they supported one another to communicate with people with intellectual disability. These were often ad-hoc strategies and supports, built upon the goodwill and skill mix of staff available at the time of crisis or need. Often staff presented these positive experiences as instances when their team worked well to piece together a strategy, rather than exemplars of systems designed to accommodate varied communication needs. Several staff focused on how fortunate they were to work in a supportive team. A staff participant relayed an experience which illustrated the way staff at their generalist mental health Agency developed a resource when specialist staff were unavailable:

So for one patient we had here, he was non-verbal, we had photos of everything. He loved to see your ID and see your photos so he knew who you were. So at first, we didn't know, so he was grabbing at us, so we were thinking, "Oh, what's going on here?" but then when we found out, no, he really likes photos and things like that. So we used that and we have like a photo book that we used.

This quote exemplifies several similar experiences discussed by staff. Offering appropriate communication strategies to service users with intellectual disability was a result of individual staff commitment. A medical practitioner also commented, 'there is a major factor ... the human factor ... some people go the extra mile'. Chance, and a willingness of staff to offer something extra determined whether accessible communication was available, rather than Agency systems equipped to meet this need. Several mental health staff appeared to view the task of finding appropriate communication strategies to work with people with intellectual disability as outside their skillset and area of responsibility.

Most staff at Agencies 1 and 2 said that they consulted with specialist intellectual disability mental health workers, or other staff experienced in intellectual disability working in generalist roles to help them to provide accessible information. Agency 1 and 2 staff valued input from specialist intellectual disability staff, although several commented that it was not always available at the time of need or in a pre-emptive capacity. Similarly, Agency 1 and 2 did not consult speech pathologists to assist in communication with people with intellectual disability. The Agency 1 and 2 intellectual disability specialist staff said that within current ratios of specialist staff to generalist team members it was difficult for them to provide more than reactive or targeted support at a time of urgent need. This resulted in limited opportunities for the specialist worker to support staff to develop and maintain skills in communication or in the development of generic accessible information for working with people with intellectual disability. A specialist intellectual disability consultant emphasised the need for ongoing training and collaborative support:

If there's no active follow up afterwards [after training] to support that change in practice, then training very much just sits alone or stands alone.

Several staff emphasised the need for training in communication with people with intellectual disability, including accessible communication resources and how to use them effectively.

### 5.3.2 Availability of accessible information resources

All of the participants with intellectual disability valued accessible information, but had not had access to easy read in a healthcare setting. Similarly, Agency staff who used easy read and similar resources said the difficulty they had locating appropriate resources had a direct

impact on their capacity to provide accessible information. Staff from all agencies said that accessible information, such as easy read, was not readily available, as reflected in Table 10.

The strategies staff used to make information more accessible for people with intellectual disability varied between agencies. Staff at Agencies 1 and 2 occasionally adapted information with support from specialist staff, but primarily accessed communication resources tailored for people with intellectual disability from the family or carer, whereas staff at Agencies 3 and 4 regularly created and used resources to enable access to information. Nevertheless, staff across all Agencies identified common issues with finding or locating accessible information, and this impacted their capacity to facilitate access for people with intellectual disability.

#### *Finding ready-made resources:*

Staff said that their capacity to provide access to information was restricted by the limited availability of easy read or accessible versions of standard health material. At Agencies 1 and 2 many staff were unfamiliar with easy read or accessible information as an option, but expressed that they would use them if they were available. At Agency 3, staff were aware of the benefits of easy read and one staff member reported, 'There are accessible mental health materials that exist, but they are hard to find'.

This quote reflected that some staff were aware that accessible health communication guides and resources were available but regretted that many hospital staff were unaware or had not taken time to access these materials, as described in Section 5.1. Another practitioner at a specialist intellectual disability service conveyed a sense of injustice that accessible information about common subject areas was not readily available for download

and use. She stated, 'But again we have to make all that from scratch, which we don't mind, but for non-ID people it's already there'.

Practitioners said that greater availability of frequently used information in accessible formats would be beneficial, as staff often faced a tension between taking time outside of face-to-face visits to create or locate resources. A specialist intellectual disability allied health staff member said: 'I think because we are so busy working on everything else we don't have time to make handouts ... but it would complement what we do'. Many staff who had limited accessible information available to them were enthusiastic about the potential of greater access to easy read.

#### *Tailorable information*

Many staff said that standardised, static information was beneficial, but insufficient to meet the needs of all their clients. They said that limited availability of and time to find suitable resources led to informal or unconventional communication options, for example:

Often a pen and paper is more convenient [to draw a picture] if the practitioner is effective at drawing, but difficult for those [practitioners] not as confident [at drawing].

The use of pen and paper described in the quote above was typical of other staff anecdotes which revealed a reliance on ad-hoc methods and dependence on skills staff may possess by chance or good fortune. Several staff said that their agencies would benefit from more visual resources that were easy for staff to access, tailor and use.

A suggestion flagged by several staff participants was the development of downloadable, tailorable, easy read information about things that are hard to explain. For example, a nurse working in an inpatient service spoke about the difficulties faced by nursing staff when

patients requested 'leave'. The participant highlighted that information in various languages is available online, but no simplified information:

So I think the language stuff is online, so you can just download it, so it's not available during things [appointments]. I think if we have that option [of downloading information] at least then you know there's certain people who come in who struggle to understand some of the things – like we talked about leaving, “As a nurse, I can't give you any leave. It's not up to me, it's the doctors,” and they're like, “Why? You're the one that opens that kind of conversation,” and that's good. That comes down to the legalities, the section and things. So if we had something like that, I think it would make it a lot easier.

#### *Adapting standard resources:*

Some Agencies permitted staff to make accessible documents for individual service users about aspects of care, but often prohibited adaptation of mandated standard forms. Several staff said that simplifying documents was problematic due to Agency policy and procedure which made gaining permission to make amendments to forms time consuming, tedious and often prohibitive. A medical practitioner working in an inpatient mental health service commented:

There is definitely a forms committee and you have to go to the district forms committee before it's officially ratified and given out to relatives or patients and things like that. But probably the ways around that, if we would give them some information, we will give them some information patients or whoever as long as it's an individually-developed patient, then it's alright. If it's not some blanket form and

give it to everybody, then it's a different matter. It hasn't got New South Wales Health, LHD, the logo on it, then it's fine.

Other staff members discussed the use of electronic medical records and described the difficulties creating access. An allied health practitioner working in a generalist mental health Agency discussed access to information in care plans:

I mean this is the other thing now with the introduction of electronic medical records, it makes it a lot more difficult or there's an extra few steps where if you have a clinician out in the road seeing someone, they'll work on a care plan together. The clinician will go back to the office, type it into their EMR, do they print it out? When they get printed out, they're all fully in size-eight font, in Times New Roman, and it's completely non-engaging. It's not well-structured and it relies on the clinician again to take the time to maybe put some thought in, to have a structure there, EMR notes. It relies on their ability to develop a smart goal or smart goals and to print it out and take it back next time or to email it to the person or however they do it.

Staff experiences highlight the inaccessibility of current mental health planning practices. Staff spoke about the reliance of services on individual staff doing extra work rather than providing readily available accessible information. The implications of current record keeping and planning systems for people with intellectual disability are explored further in Chapter 7.

### 5.3.3 Agency policy and procedures

Several health Agency staff said that policy expressed ideals about supporting diverse communication needs, but did not include strategies to support them when communicating with people with intellectual disability. This analysis reinforces the findings in the policy analysis which exposed limited direction for staff about communication with people with intellectual disability (as discussed in Chapter 4). Staff at the health Agencies identified that Agency policy, including guidelines and procedures, were essential to support them to facilitate access to information. Several staff articulated that to facilitate access to information consistently, they needed more detailed policy and procedure to support the flexible practices, staff training and resource availability described above.

Many staff at Agencies 1-3 suggested that practical strategies were absent or insufficient in their agency's documentation. A staff member experienced in supporting people with intellectual disability captured a central finding of this research about policy and access to information:

Values and principles are fantastic – people need to be respected, understood and communicated with in a particular way ... whether it happens for this population [people with intellectual disability] I am not sure ... there is a lot of good intention but it is not supported in the standard operating procedures.

Most health Agency staff said that they did not have access to a clear suite of strategies or resources articulated in policy and guidelines to support them to enable access to information. They were not aware of guidelines about communicating with people with intellectual disability. Similarly, most staff were not aware of any guidelines to support them to create accessible documents at their agency. Some staff said that the overarching



principles of the UNCRPD were evident in policy. For example, a specialist intellectual disability worker at a mental health Agency commented:

The things that do come to mind on a national and state-based level is the national mental health recovery framework and the living word document that the commissions put out, obviously, as well as the UN Convention on the Rights of Persons with Disabilities which says that we should be doing all this stuff. But in terms of what's actually more tangible, the how-to, and then what provisions are made to support starting that process, no, I haven't seen anything like that in this space, no.

Several Agency staff said that they valued flexibility when communicating with service users which they often attributed to a supportive manager rather than supportive policy. Staff saw that their ethical responsibility to communicate in a manner that suited people who accessed their service overrode agency rules. A manager at a generalist mental health Agency stated:

So I guess my job is to make sure that nothing underhanded is going on but if one of my staff comes to me and wants to develop some things specifically to have a patient then I'm going to be totally supportive of that even if it contravenes some LHD policy.

Many staff were not confident in the guidance they received in policy documents and several staff expressed a reluctance to explore whether their agency had relevant policy. For some, the reluctance appeared to stem from a desire to avoid rules which impinged on their practices and others felt overwhelmed with administrative tasks. For many staff, policy was

seen as an added pressure, often irrelevant to their core duties including communication with people with intellectual disability. For example, a staff member said:

I have no idea how the policy impacts my work ... I feel like I come to work, do what I want to do how I need to do it and I have no idea how that interacts with the policy and procedures.

Another staff member stated: 'Policy and procedure has very little impact on the day-to-day running of the department'. Many health Agency staff said that they would value more practical, relevant direction and expressed enthusiasm for increased availability of accessible information, such as easy read.

Staff experienced in creating and using easy read were unanimous about its benefits and enthusiastic about policy support, however some expressed caution about agencies mandating, or strongly advocating its use. Easy read creators were concerned that sometimes agencies felt they had met their obligation to offer access to information by providing easy read documents. An Agency 4 staff member commented, 'That's the fear often with readily available material ... whether that makes people feel I have ticked that box ...'. Similarly, an experienced practitioner at Agency 3 suggested that at times, accessible information could be tokenistic. This participant emphasised the importance of tailoring information, and the danger of routine practices that lessened the need to consider individual communication preferences. These concerns were reflective of those raised in the United Kingdom where easy read health information has been mandated (this is discussed in Chapter 8). Experienced easy read creators said that it was important for policy to support staff to provide accessible information, with opportunities to tailor how and when it was used.

In summary, the availability of accessible information such as easy read depended on staff skill, commitment and knowledge rather than on clearly articulated agency obligations or processes. Many staff seemed unaware of their obligation to provide tailored information but expressed a desire to do their best to support people with intellectual disability. Despite this goodwill numerous staff lacked confidence, skill and direction in how to enable access for people with intellectual disability. Staff indicated that information was easier to make accessible where there was a respectful, supportive and collaborative Agency culture. Staff also identified some common features of Agency processes that supported them to enable information access. The key features of policy and agency processes that support staff are defined from the interview data and summarised in Table 11.

**Table 11: Summary of policy and Agency processes that support information access**

Policy features	Agency structures and processes
<ul style="list-style-type: none"> <li>○ Recognise the right of people with intellectual disability to access service and information</li> <li>○ Articulate the Agency obligation to provide accessible information</li> <li>○ Provide instruction for staff about communicating with people with intellectual disability</li> <li>○ Support structures and practices described.</li> </ul>	<ul style="list-style-type: none"> <li>○ support ongoing mentoring</li> <li>○ incorporate readily available accessible information as well as tailorable communication options</li> <li>○ accommodate flexible appointment times, formats and locations</li> <li>○ allow opportunities to build relationships with people with intellectual disability</li> <li>○ include family or carer when appropriate.</li> </ul>
Source: Participant interview data	

## 5.4 Summary of *access* to information

When thinking about the experience of Lara and her family alongside the reflections of staff at the health agencies, it is quickly apparent that the concept of access to information is complicated. In Lara's situation, as discussed, she was using a service which was well equipped, had access to medical knowledge and interpreter services, and she was accompanied by a paid support worker, yet she still did not have access to her information that she had a right to access. Lara's story illustrates the interplay between agency

structures and the myriad of relationships which form the healthcare team that supports access for people with intellectual disability.

The availability of easy read and accessible information was one factor of many that impacted whether people with intellectual disability actually had access to information. When people with intellectual disability discussed the concept of access, the attitude of staff as well as opportunities to interact, were paramount. The attitude and skill of practitioners impacted the information or choices provided to people with intellectual disability, including whether accessible information was used. Staff across all Agencies recognised the need for systemic support to enable them to provide access to information. A manager at a general mental health agency captured the fundamental role of relationships and Agency culture in her comment:

You can create the best, the most evidence-based, well-researched piece of work [easy read or accessible communication resource] and then if it just sits on the side and people don't actually pick it up or people don't have quality relationships with people, where there is that established trust and rapport, openness and curiosity to support practise and relationships and health, it can only go so far.

The findings about access to information provide a foundation for the chapters that follow. The exploration of how agencies meet their responsibility to make information available in this *Access* chapter provides the basis for exploring how easy read is used to facilitate understanding in Chapter 6, and ultimately appraise and apply health information in Chapter 7.

## CHAPTER 6: UNDERSTANDING INFORMATION

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This chapter is about people with intellectual disability understanding mental health information. *Understanding* is the second element of obtaining health information in the integrated health literacy framework (Figure 1). Sørensen et al. define understanding as ‘the ability to comprehend’ the health information accessed (Sørensen et al., 2012, p. 9 ) The data are from the interviews and resource mapping. The findings in this chapter relate to all of the research questions outlined in Table 3, but contribute most to research question 2: *How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?*

As argued in previous Chapters, the activity of understanding information can involve individual skill, preference or ability, coupled with support from others. Understanding information links closely to accessing, appraising and applying information, and the findings across Chapters 5-7 reflect this interdependence. Tran’s experience getting general health information is used to introduce the concepts in the chapter.

### TRAN

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Tran came to the interview on his mobility scooter. He communicated with some spoken words, as well as via text on his phone and with simple signs. Tran was in his mid-30s, had a

part-time job, lived with his family but planned to move out soon. His family were supportive of his plans. He said that although he liked to do things independently and did not like to bother his family, he usually went to medical appointments with his parents.

Tran said he was frustrated at the difficulties he experienced in getting health information he could understand. There were lots of silences as Tran typed his answers during the interview – he often seemed quite frustrated at the time it took him to convey his answers.

Tran answered with the phrases, ‘it’s hard’ or ‘it’s hard for me’ via text and verbally repeated them throughout the interview.

Tran said that to understand health information he prefers short sentences, small words and pictures. Tran’s doctor talks to him and gives him time for questions, which he values. When making decisions Tran prefers written information to review later as discussing things verbally is difficult, especially on the phone. He typed that he appreciated ‘Lots of information and to think about it’ when making health-related decisions. Tran also identified video as a valuable source of information for him. When asked if there was anything else he wanted to say, Tran added that it is important to him that he has correct information. He texted, ‘Make sure it’s the right information’.

A significant obstacle that Tran identified was that the family members he took to appointments often found it difficult to understand the information that was discussed.

Tran said that his family only speaks Vietnamese and cannot read English. Tran speaks English and Vietnamese but can’t read Vietnamese. This makes shared understanding of complex issues difficult for Tran and his family.

Tran was familiar with easy read in disability service settings. He has found it to be very useful for him and his family as they are all able to understand it. The words are short and

the pictures help him to understand it and his parents often can too. Tran said that easy read health information would make a big difference for him. Tran did not use mental health services, but his experience has implications for similar encounters involving mental health.

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This chapter presents findings from all four participating Agencies, first focusing on the mental health service context and the strategies that staff at health Agencies used to make information easier to understand. It then explores how easy read was used by health staff, and by people with intellectual disability, to enhance understanding. It concludes with some reflections about the potential for greater use of easy read in the mental health service context.

## 6.1 Facilitating understanding at mental health Agencies

Staff identified many challenges in the mental health service environment which impacted opportunities to support people with intellectual disability to understand information. Mental health agency staff were particularly aware of the impact of episodic mental ill-health on understanding by many of their service users, including people with intellectual disability. The challenge of fluctuating levels of understanding further reinforced the importance of establishing relationships to tailor communication. Staff reinforced that the social and environmental influences which impacted access to information (identified in Chapter 5) also impacted opportunities to understand information. This section explores the impact of mental ill-health, the benefits of establishing relationships with people with intellectual disability and engagement of family or carer to facilitate understanding.



### 6.1.1 Impact of mental ill-health

The impact of mental ill-health on understanding and communication was most evident in interviews with staff working in an inpatient setting. Many staff expressed that people's levels of understanding often fluctuated throughout their stay. Staff were aware that in an acute setting, service users were not always receptive to interaction or verbal information exchange. This impacted the ability of service users to communicate effectively. A medical practitioner working in an inpatient unit reported:

Now, sometimes the problem with that for us is that our patients when they come here are usually really, really unwell. So no matter what we do in terms of trying to indicate something, it's impossible to get that information across.

The above medical practitioner grappled with the demands of the inpatient setting and said that often staff would re-visit the service user as their level of understanding improved. However, they were unsure that service users were always given adequate opportunities to engage with admission information once the initial opportunity had passed.

Some staff said that they found it particularly difficult to communicate with people with intellectual disability who they had not met or worked with previously. Several staff said that having a knowledge of people's baseline skills and preferences was important, and that this impacted the ability of staff to communicate effectively. A specialist intellectual disability staff member participant described a situation when staff incorrectly assumed that a woman with intellectual disability using their service was permanently unable to communicate verbally. The person with intellectual disability was usually able to communicate, but had lost this skill as she was experiencing psychosis. Hospital staff

assumed that because the service user had a diagnosed intellectual disability her inability to communicate was permanent.

The changes in understanding due to the episodic nature of mental ill-health highlighted the need for staff to engage and tailor information throughout their interactions with service users. Staff emphasised the need to check understanding regularly and revisit concepts during and after contact with all service users, and even more so for people with intellectual disability. These findings further emphasised the benefit of the Agencies supporting staff to provide additional opportunities for questions and clarification as required.

#### 6.1.2 Establishing relationships:

The participants with intellectual disability valued respectful relationships with service providers because they fostered trust. Trust was important for people with intellectual disability to indicate which communication strategies they preferred and to clarify questions as they arose. The characteristics of supportive relationships described in Chapter 5 had particular benefits when considering the task of understanding information.

One of the benefits of establishing a relationship was the opportunity for service users and service providers to ask questions. Numerous participants identified the importance of asking questions to develop understanding. A participant with intellectual disability spoke about the link between his relationship with his GP and opportunities to ask questions. He commented about his GP: 'She [GP] is always happy [obliging]. She is open to me to asking questions – if you don't ask questions then how do you find out answers...'.

The people with intellectual disability highlighted the importance of two-way communication to facilitate mutual understanding. For example, a participant with intellectual disability shared what she would like health practitioners to do:

Listen more – don't talk too much and listen more and ask questions ... if you get to ask them questions and they should also ask you questions if they don't understand ... ask questions ... open communication... don't rush them, make sure you're clear and they're clear about what is going on and what is being said.

Similarly, staff across all health Agencies also said that the most important aspect of communicating in an understandable way was to 'know the patient'. Staff highlighted the benefits of knowing the service user's developmental level, current social situation and mental health condition as well as their communication preferences, literacy levels or cultural needs. Staff at Agency 3 also commented that getting to know the service user in person was essential, as referral information 'on paper' did not always reflect the patient's level of understanding, health priorities or motivation.

Several staff said that establishing rapport with service users with intellectual disability can reduce the likelihood of staff making assumptions about how to present information. Some staff had worked with service users who were reluctant to use easy read or other accessible information and this made it difficult for staff to tailor information. This reticence was for various reasons, often linked to service users being embarrassed about having a learning difficulty or needing simplified information. Several staff reinforced that it was important to consider these factors when tailoring communication.

Other staff spoke about the impact of their own expectations or assumptions on the opportunities they offer people with intellectual disability to interact with health

information. A staff member in a specialist disability support role at a mental health service commented that staff can misjudge the capacity of service users with intellectual disability to engage:

Sometimes there is a preconception that people [with intellectual disability] can't understand but the problem may be that you [Agency staff] are not giving the information in a format that is easy to understand.

A specialist disability staff member commented that staff needed to be able to establish relationships to 'follow the person with intellectual disability's lead' about communication. Following the lead of people with intellectual disability in this case related to negotiating appropriate communication strategies, and included navigating how family or carers could support communication.

#### 6.1.3 Engaging family or carers:

Many practitioners said that they found it beneficial, but at times challenging, to navigate family relationships when seeking to establish a relationship with people with intellectual disability. Some of the participants with intellectual disability relied on family or carers always to communicate their needs and preferences; for others this varied according to the type of health problem and purpose of the appointment. The findings about family engagement and understanding reflected the need for health practitioners to ask service users about the role of family or carer throughout the period of service provision.

Staff said that there were many benefits to including family or carer when seeking to make information understandable. Many staff valued the support of family or carer to facilitate their communication with service users with intellectual disability during and after appointments or admission. The staff at a generalist inpatient mental health service

commented: 'We use family and existing carers to facilitate communication where possible – works in 90 per cent of cases'. Several staff valued family input to tailor information to make it more relevant and understandable. Several staff participants at inpatient mental health Agencies mentioned 'group home staff' as a key source of information about routines and preferences, including communication strategies or resources. At Agencies 1 and 2, families or carers were identified as the source of communication aids to assist with routines, and these aids were often in easy read format..

Staff said that using family or carers as a conduit for information and communication strategies was vital but it had at times hidden the need for Agencies to supplement the communication with appropriate resources. Some staff raised concern that the dependence on family or carer or other agencies to support communication masked or compensated for the lack of accessible information available within their agency. They said their reliance on communication support from outside the health Agencies at times perpetuated staff's limited awareness of accessible information and their Agencies' obligation to provide it.

There are many challenges for staff and people with intellectual disability seeking to communicate in a mental health service environment. Section 6.1 has established that episodic mental ill-health and the environment of mental health services can impact effective communication for many services users, including people with intellectual disability. Staff emphasised the importance of establishing relationships with people with disability, and their families or carers, to facilitate understanding. These relationships can provide a venue to discuss and negotiate which communication strategies and supports the person with intellectual disability would find most useful. Section 6.2 explores the strategies staff used to make information more understandable.

## 6.2 Strategies used to make information easier to understand

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Many health Agency staff were concerned that the information routinely provided at their agencies was not understandable to service users with intellectual disability. Mental health Agencies did not often use easy read, and little information was available in accessible formats as illustrated in the resource mapping (Table 10). Instead of using accessible text formats, some staff identified a suite of strategies they used to tailor communication to facilitate understanding when working with people with intellectual disability. Some staff across all Agencies emphasised the importance of having many options to use with people with intellectual disability and their families or carers. The communication described by staff was often based on verbal exchanges, using adjunctive strategies to enhance understanding. The key communication strategies that staff identified in the interviews were verbal exchange, pictures, varied modes or strategies, and written information.

### 6.2.1 Verbal exchange

The method of communication used most commonly at all health Agencies when working with people with intellectual disability and their families was conversation and verbal explanation. Participants with intellectual disability said that it was important to their understanding that health practitioners use clear, concise, concrete messages with a focus on the main points, and easy words when discussing health information. They said that including both the person with intellectual disability and people who support them in the appointment was also important. When talking about a medical consultation a participant with intellectual disability stated:

It's two ways, I mean that's what they're there for ... Yes it's a two way thing ... it's not a one way thing ... it also can go to three ways if you take someone with you.

Similarly, some staff valued two-way verbal communication as this gave service users time to consider information and ask questions. The staff that used this strategy said that it enabled them to check that the service user had understood the information and gauge their level of understanding so that they could pitch information at an appropriate level.

Several staff spoke about strategies that they employed to increase understandability. These included using short sentences, repeating ideas, keeping language simple and limiting jargon. An allied health worker at a generalist mental health service said:

I guess to limit the number of words I use and the number of words in a sentence. So I try to avoid complexity. I use repetition. I use a lot of space for conversation and questions and may use more examples or analogies, particularly for abstract concepts like consent.

Many staff said that it can be difficult to think of appropriate terminology and avoid jargon. A staff participant used an easy read style script to structure verbal exchange, for example, when people had many questions about the service and the logistics of attending. She felt that this was an effective reminder for her to convey only the information required, and in a simple way. An allied health worker in a generalist mental health service provided an example of the ways in which she adapted communication to suit people with intellectual disability:

you would vary language ... you make sure that you are using language that can be easily understood and I would probably mirror some of the language that they're

using ... so I knew that that was the language that they knew and understood, and I would probably ask for – if we're talking about something, I would ask for their understanding of what we're talking about and so we're clarifying things along the way, making sure that we're on the same page, if you like. I probably would do that more so than I would other patients.

### 6.2.2 Visual information

Some staff accompanied discussion with pictures or diagrams at the time of the appointment to explain concepts, and others gave paper-based information to take away from the visit (a practise discussed further in Section 7.2.2). All Agency 1-3 staff said that visual information such as diagrams and pictures was an essential tool when conveying information about health and health services. Staff who used visual aids explained the need for accompanying text or verbal explanation to ensure an accurate understanding of the visual information.

Many staff said that there were benefits to using pictures to accompany verbal explanations, as well to accompany text-based information. Some staff used ad-hoc visual resources such as a pen and paper or a whiteboard to draw diagrams and symbols. These aids included pictures such as faces, flow charts and thermometers to illustrate feelings or stages in a process. Several staff at Agency 3 emphasised that effective communication was usually facilitated with visual representation and simple words in combination, rather than words or pictures alone.

### 6.2.3 Varied communication strategies

Several staff said that when working with people with intellectual disability and their families or carers, communication was most effective when strategies included various



media. Some staff described varied strategies within the same appointment and others identified the need to modify communication according to appointment type. The variety of strategies included gestures or acting out information, specific communication apps or technology, video, art-based activities and tailored combinations of these options. A participant with intellectual disability said that health practitioners need to:

Put yourself in the patient's shoes and then once you think right this is [name] ... I've got this as my next patient, how am I going to make it easy?

Staff members at two health Agencies commented that gestures were a valuable accompaniment to verbal conversation, which echoed similar comments made by people with intellectual disability. Although not a strategy widely used by their colleagues, some staff felt that acting things out or modelling an activity was a valuable tool for all age groups. A specialist intellectual consultant working at a generalist mental health service said:

And I'll model the action. So I find then people understand. If you deliver it only verbally – no, no – so then, I found clinicians tend to find a bit – they get a bit embarrassed about using too much gestures, even modelling them.

The benefit of using gestures or modelling was evident in the vignette about Raelene's experience at the start of Chapter 7. Raelene valued her GP modelling how to use an asthma puffer. She said, 'So you've got to be able to communicate properly but you also need to be able to show someone how to do it'.

Agency 3 staff used the term 'multi-modal' to describe communication that involved various forms of communication. Using multi-modal communication is recognised as a valuable strategy when working with people with intellectual disability (Iacono et al., 1993; Pinazo, 2017). Agency 3 practitioners had developed a set of resources for use in therapy which

presented the same information in different ways, teaching skills verbally, via video and on paper. The features of multi-modal communication that staff identified which made it effective for people with intellectual disability were the appeal of the screen/technology, the value of repetition and the opportunity to tailor information to the individual service user's interests and learning style. The mode and mix of communication strategies varied according to session type and service user needs. Similarly, a practitioner said that it was most effective to have multiple communication options for parents/carers. He suggested the use of web-based resources for families to access as they need them, with resources such as video and College of Psychiatry information about mental health.

The challenge identified by some staff was having the tools to give information that service users needed when they needed it, without overwhelming them with superfluous detail or information not yet required. The exercise and nutrition staff spoke about a scenario when they tailored strategies to encourage service users and their families and carers to adopt strategies. For example, these staff reported that they had used mainstream nutrition resources, such as posters and flyers. These resources had too much information or too many steps to complete, which reportedly overwhelmed service users and their carers/families and resulted in inaction. They created personalised resources with a variety of targeted communication modes, such as video to demonstrate exercises, numerical representation, and easy read charts, which proved to be more effective.

#### 6.2.4 Written information

At all Agencies, written information was an essential element of agency communication. All staff relied on written information to tell patients about their service, provide information about their mental health conditions, and to inform people about their rights or gain

consent. Staff at all health Agencies thought that written information was valuable, but they were concerned that many of the written documents they passed on to service users were difficult to understand. Most staff said that the content of documents and mandatory forms were not always easy to explain verbally, pictorially or with other varied communication modes. This made using mandated written information problematic. The findings about written information primarily related to mandated forms and agency information, information about health conditions and the need for support to understand written information.

Staff at all Agencies said that they found standard agency documentation difficult to use when working with people with intellectual disability. Chapter 5 introduced these issues. At Agencies 1 and 2 for example, staff had standard forms for use at admission and staff working with involuntary patients used mandatory written material to inform new patients of their rights. Staff working in inpatient settings explained that involuntary admission brought with it the responsibility to explain the Mental Health Act to people who were admitted to care. A staff member in a nursing role spoke about the difficulties using the current format of the information about their rights under the Mental Health Act when working with people with intellectual disability. Many other staff working in inpatient services made similar comments:

So if somebody is here under the Mental Health Act that they have to be given – that’s one thing that definitely has to occur [provision of information about the Mental Health Act], and I don’t think that we have – because it’s a legal thing, we don’t have anything that’s properly simplified for someone with an intellectual disability, although we have simplified information in the sense that it breaks it down

but I don't know that it would be – even for them it would be easy to understand because it's just jargon in there and all that sort of stuff.

Another staff member from a mental health inpatient service commented:

So everybody gets a welcome pack but nobody really goes through it with them.

Probably the level of understanding, particularly in these patients that I'm thinking of [people with intellectual disability] would've been pretty poor ...

The volume of information contained in reports and the language used often made the information difficult for service users and their families to understand and use. At Agency 3, for example, often families completed numerous forms and read written information before and after the appointment. Some staff at Agency 3 raised concerns that much of the written information provided was directed toward families and carers rather than the person with intellectual disability. An additional concern raised by some Agency 3 staff was that the information sent home from appointments was sometimes difficult for families and carers to understand, which in turn impeded the capacity of family members to explain the implications to the service user with intellectual disability. A medical practitioner at Agency 3 discussed the dilemma of providing report recommendations to family and carers, 'Even though our reports are very comprehensive they are very intimidating ...'.

In addition to the mandatory forms and agency documentation, mental health staff said that they did not have adequate access to accessible, easy to understand information about mental health conditions or treatments. Staff participants at a generalist mental health Agency for example, were unanimous that written documentation was not tailored to meet the needs of people with intellectual disability. This included information about treatment

and tools and activities used in therapy sessions. A therapist commented about inpatient session material related to anxiety:

Sometimes I will use handouts that are slightly mismatched but with the explanation to them, "I'm using this because of this. I think disregard that, this would be helpful", but I think that that's too complex for somebody with an intellectual disability.

Several staff at Agencies 2 and 3 said that one way they seek to make written information more understandable was to read through it with people and give opportunities to discuss it. This practice was highlighted as particularly important for people with intellectual disability or limited literacy. An allied health worker in an inpatient service commented on the consent and confidentiality information available at their agency:

I don't think it would be accessible for someone with say, a mild intellectual disability, but we never have it with the intention of just handing it over with everyone. We go through it paragraph by paragraph. They're pretty complex concepts actually.

The quote above indicated that staff were aware of both the complexity of documents they used and the need for interaction with people with intellectual disability to facilitate understanding. The concern raised by many staff was that they lacked the time to read through and explain information be able to meet the needs of people with intellectual disability adequately. This issue was evident at all health Agencies and was exemplified by staff working with people in an inpatient setting who were required by law to convey information about the Mental Health Act. Some staff participants provided many examples of opportunities to modify documents, add pictures, use visuals or simplify language to make information more accessible, but some staff were concerned that this practice was

not always possible with standardised agency documents. The difficulties many staff encountered when using mandatory written documentation highlighted the need for more accessible options and the potential for written resources that are easier to understand.

## 6.3 Easy read about mental health

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Easy read is one strategy that may assist staff to make information more understandable.

The focus of this section is on how easy read was used and its potential to be used more.

Findings about the benefits of easy read for a broader audience were included, but not emphasised, due to the focus of this study on intellectual disability and easy read. This section examines what people who used easy read said about using it to make information easier to understand, concluding with a brief exploration of the potential for further use of easy read.

### 6.3.1 Easy read at the health agencies

The value of easy read to increase the understandability of information was undisputed at Agency 4 and by people who had used it in health Agencies. The use of easy read varied across the four Agencies (as discussed in Chapter 5). The participants with intellectual disability were passionate about increasing the availability of easy read and used it themselves to facilitate their own understanding in various settings. The examples in Appendix 21 illustrate the diverse applications of easy read at Agency 4. At the time of the interviews, none of the participants with intellectual disability used easy read information in medical appointments or health settings but they saw many possible applications. The findings emphasise the benefits of using easy read to facilitate interaction and the mutual

benefits for service users and providers. These benefits are discussed before focusing on easy read design and the broader applications of easy read.

### 6.3.2 Facilitating interaction

All of the participants with intellectual disability valued easy read, but they emphasised that respectful conversation and support was more important in enabling understanding than just the design or technical details of easy read documents. They said that respectful relationships to support people with intellectual disability to use easy read were crucial to enabling understanding, across varied communication strategies. Some people with intellectual disability used easy read independently but most people used easy read with support from others to facilitate understanding. A participant with intellectual disability described easy read as 'living documents', designed for use within conversations with other people.

Many staff emphasised the importance of developing relationships with people with intellectual disability and their families or carers when using easy read to support understanding so that information could be tailored appropriately. Some staff at Agency 3 highlighted the importance of getting to know the person with intellectual disability to choose how, when and to whom they provided easy read information. Many of the staff who used easy read described using it to facilitate information exchange, explain concepts and revisit information. A specialist intellectual disability consultant working at a mental health Agency described this as, 'Not just give this [easy read document] and goodbye'.

### 6.3.3 Mutual benefit

Some participants with intellectual disability and some staff said that using easy read had potential to benefit both the health practitioner and the person with intellectual disability.

Easy read users said that it provided more accessible words for the person with intellectual disability to understand and it also acted as a resource for practitioners. A participant with intellectual disability explained that simplifying information is often quite difficult. She saw that for doctors, easy read made them use appropriate words, which was beneficial as doctors are often more familiar with technical jargon or medical terminology:

It's hard to explain about easy read 'cause unless you've actually got it in front of you trying to put something in easy read terms can be pretty hard – it's kind of odd word easy read because when they are at medical school they don't put things in easy read they put it in medical jargon ... and then they've got to try and decipher it.

Staff across Agencies 1-3 gave examples of how they used easy read to tailor or pitch communication to meet the needs of people with intellectual disability and families or carers. Several staff explained that having easy read can remind service providers to use appropriate terms to convey messages. This was relevant for interactions with both family or carer and service users with intellectual disability. Staff highlighted that many family members and carers also have difficulty understanding concepts and easy read was an effective prompt. In a clinic or appointment setting a staff member said that easy read 'Sets the tone and acts as a reminder in the relationship'.

#### 6.3.4 Design

When creating easy read resources, several staff emphasised the importance of choosing the right content to include, and this included the choice of appropriate images to accompany text. Several Agency 3 staff described the advantages of a picture to accompany simple text information in easy read, but also highlighted the importance of choosing 'the right picture'. For example, staff found that some service users found generic photographs



helpful, but for others, photographs or pictures of specific sites or people were more effective, especially if the person 'is a concrete thinker'. Staff involved in providing exercise sequences, for example, reflected on the value of charts and photographs or line drawings to convey what to do and how often. Agency 4 provided informative feedback about the design features of easy read (see Appendix 21).

#### 6.3.5 Easy read for a variety of service users

Participants with intellectual disability spoke about many situations they or people they know used easy read to meet various needs. This is evident in the vignette outlining Tran's experience at the start of the chapter. Tran saw that easy read was useful for his parents as they had limited ability to understand and read English. Participants stated that easy read resources also have broader applicability, for example for people who are stressed, have vision problems or limited literacy. A staff participant working in a specialised intellectual disability role commented:

I think easy read, like whilst it's great for kids with intellectual disability I think it's also quite handy for other people as well who are overwhelmed with information.

Another staff participant working in a generalist mental health support role commented about the broader uses of easy read:

People don't want to read a lot. People want simple information. Plus not only [people with] intellectual disability, we have got a lot of clients that are illiterate and they need the visual, pictures.

A practitioner at Agency 3 used accessible information for professional education workshops, for example, and found that, 'They are just universally useful'. This reflected similar findings about the wider appeal of easy read in the literature (Meppelink, 2015).

Many staff highlighted the value of tailored strategies, and easy read was among the suite of tailorable options identified by staff at Agency 3. Agency 3 staff said that easy read was one of the strategies they used to reduce the amount of information provided and to explain what the person needed to know, when they needed it. A specialist intellectual disability consultant at a generalist mental health service explained: ‘So for me, I think it needs to be time-specific, this is what you need now, this is what can help you now’.

The findings about understanding information were closely linked to using easy read to appraise and apply information. The suggestions that staff made about the kinds of information that would be useful in easy read format at their agencies are incorporated in Chapter 7.

## 6.4 Summary of *understanding* information

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Many of the staff interviewed in this project were not satisfied that service users with intellectual disability at their Agencies had access to information that they could understand. Staff used a variety of strategies to make information easier to understand and many staff thought that easy read would be a valuable addition to the suite of communication strategies they currently used. The most consistent finding about *understanding* was the importance of tailoring information to suit the individual’s needs at the time of the interaction.

To tailor information, staff needed to have the opportunity to establish rapport with the service user and access to appropriate communication strategies. These findings reinforced the need for appropriate staff training and availability of resources, as outlined in Chapter 5. In the mental health service context, staff said it was important to consider fluctuations in

understanding and highlighted the value of engaging the family or carer when tailoring communication. Many participants were aware of the value of the family or carer to facilitate understanding, and also the potential for the role of families or carers to change over time.

These findings provided insight into the 'environmental and situational' influences denoted in Sørensen et al.'s (2012) model. The dynamic nature of relationships and agency practices to support people with intellectual disability to understand health information was evident in the data. Participants identified that relationships between people with intellectual disability and families or carers, as well as health practitioners, often changed for various reasons, such as life stage, appointment type or personal preference. The staff who used easy read valued the ways that it can be used to make information more understandable in the context of supportive relationships.

The people with intellectual disability who participated in this project used easy read to increase their understanding about various topics. Tran's story is an example of both the factors that impact communication, and the potential for easy read in his situation. The people with intellectual disability and staff who used easy read said it was most effective when used in the context of supportive relationships, and as one option of many options. People who used easy read recognised its value in enhancing understanding, but the significance to people with intellectual disability was in the opportunities to use the information they had learned. Using easy read to discuss information and make decisions related most directly to the tasks of appraising and applying information in Sørensen et al.'s (2012) integrated health literacy framework. Using easy read to support understanding has

potential to significantly impact processes surrounding appraising and applying information and this concept is explored in Chapter 7.

## CHAPTER 7: APPRAISING AND APPLYING INFORMATION

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This final findings chapter explores the concepts of *appraise* and *apply* from Sørensen et al.'s (2012) integrated health literacy framework. Appraise describes the ability to interpret, filter, judge and evaluate the health information that has been accessed, and apply refers to the ability to communicate and use the information to make a decision to maintain and improve health. As described in Chapter 3 and reflected in this research, these activities are embedded in relationships of support, particularly for people with intellectual disability.

The task of appraising and applying health information builds upon the elements presented in the access and understand chapters (Chapters 5 and 6). The findings about appraising were similar, and at times difficult to distinguish from those about applying information. To avoid repetition, findings about these concepts are presented as a single chapter.

The findings in this chapter relate to all the research questions, but most directly to question 2: *How is easy read and accessible information used by people with intellectual disability in mental health services?* and question 3: *How do people with intellectual disability and the people who support them use easy read?*

Raelene was not a user of the participating mental health services. Raelene's experience is used to introduce the concepts of appraising and applying information.

Raelene was very experienced at making easy read and had thought about what made health information easier to understand before our interview. She was in her mid-40s, worked part-time in retail and was enthusiastic about promoting accessible information. As an easy read creator Raelene had insight into how she and others used easy read, but also highlighted the other ways she sought support to appraise and apply information.

Raelene had supportive family and friends who she discussed most health-related decisions with. When asked about how she finds health information, Raelene said:

Probably depends on how I am feeling at the time and whether I need extra help ... probably talk about it, ask someone who knows more.

During the interview Raelene discussed the importance of her relationship with her GP. Raelene saw her GP to discuss asthma management for various activities. Raelene said that the information she had received about her asthma medication was not always easy to understand: 'I'm slightly asthmatic and the information is pretty ... it's not easy to read!'

Raelene described the way that her GP explained how to take the medication so that it was easier to understand how to use it:

This is exactly what my doctor did – she actually got out the sample inhaler, put it up to her mouth, said you open your mouth, put the puffer in, don't bite down on it, bring out, put the cap back on and breath it back out ... she demonstrated what, how to use it.

Raelene was able to demonstrate to the doctor that she could use the puffer and felt more confident to manage her asthma when she was out. She spoke about the need to take the puffer to various locations and said that it was often a couple of weeks between the occasions when she needed to use it. Her pharmacist worked with her to create instructions in a suitable format to remind Raelene of how much medication to take:

When I went to the chemist, what they did, they said would you like it [the instructions] on the box or around the puffer? So they put it around the base bit of the puffer so I could actually read it ... They put my name, how many puffs ... so that's how they did it and it worked.

We discussed medication and the benefits of easy read in conjunction with other practical reminders. Raelene reflected that medication can be difficult to remember and manage:

I manage it myself but it can be hard ... I know that you can get those little pill boxes that you can put your pills in ... everybody is different

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Raelene's story offers insight into personal experience of appraising and applying health information. Raelene was someone who valued the ways that easy read, and other accessible information, enabled her to manage her asthma. Interaction with her GP and pharmacist provided a foundation for Raelene to confidently manage her asthma with minimal day-to-day support. The partnership between Raelene and the health service providers using tailored communication strategies was paramount to effective appraisal and application of health information. Raelene's experience illustrated the interplay between

confidence, supportive relationships and the availability of accessible information resources. Her experience is reflected in the findings.

This chapter first examines factors which impacted the process of appraising and applying information for people with intellectual disability across varied health service types. The second section presents a more focused exploration of the opportunities staff identified to appraise and apply information in a mental health service setting and the use of easy read to facilitate this process. This chapter informs knowledge about the impact of ‘social and environmental’ influences, as described by Sørensen et al. (2012), on opportunities for people with intellectual disability to appraise and apply information.

## 7.1 Factors that impact appraising and applying health information

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Many staff participants were uncomfortable with the low level of inclusion of people with intellectual disability in appraising and applying health information. Staff from all Agencies grappled with the dilemma of how to ensure that health-related decisions and their implementation reflected the preferences of people with intellectual disability. Several staff expressed concern that staff and families or carers did not always consider or explore the preferences of people with intellectual disability when making decisions. A staff participant experienced in supporting people with intellectual disability commented:

The more I think about it – it must be so hard for people [families or carers] and so easy for people [with intellectual disability] to have decisions made for them or pushed into decisions and not even coming from bad places ... probably coming from good intentions from health professionals [and] family members ... family members



must make decisions all the time about people's health and it's probably made in relation to all sorts of factors ... Making life easier for everyone.

The staff member quoted was not satisfied with current agency processes, as she had seen the preferences of people with intellectual disability bypassed during decision making in both health and disability agencies. Several staff members expressed a similar sentiment, identifying that at times, expediency, efficiency or assumptions determined the choices of people with intellectual disability. Participants identified numerous factors that contributed to the limited opportunities for people with intellectual disability to make and implement health-related decisions. This section describes the factors that influenced the process of appraising and applying information. It acts as context for the more focused examination of easy read presented in 7.2. First, findings about the impact of the healthcare context on opportunities to appraise and apply information are presented, then the role of supporters.

#### 7.1.1 Mental health agency context

Many factors impacted the opportunities available to people with intellectual disability to interact with, and consider, health information. The integrated health literacy framework developed by Sørensen et al. (2012) illustrates the varied factors that influence opportunities to interact with health information. In this research, the service environment, disability type, personality, level of support available, prior knowledge, and episodic mental health issues were among many factors which impacted the process of appraising and applying health information. Some participants with intellectual disability, such as Raelene, were very confident to appraise and apply health information and advocated for the rights of others in the health service context. Other participants with intellectual disability were reliant on family or carers to support them to interact with health providers and

information. Participants with intellectual disability, and many staff, identified that the healthcare context commonly created anxiety and impacted the confidence of many people with intellectual disability to appraise and apply information.

Many of the staff said that they were aware that the people with intellectual disability that they worked with were often hesitant to challenge recommendations or information provided by health providers. The hesitancy to speak up identified by staff is consistent with the literature outlined in Section 2.3.2. Some staff said that it was difficult for people with intellectual disability to question recommendations or engage in health decisions and highlighted that often service providers were not aware of this dynamic. For example, an experienced staff member who supported people with intellectual disability commented:

There is a very high chance that the person/patient will agree with things or say yes to things even if they don't understand or don't agree ... I think there is such a massive power imbalance ... even if the doctor isn't necessarily on a power trip it [the doctor] could be a really good person ... the person [with intellectual disability] could be anxious or nervous or whatever ... even if they're not, there is that kind of wanting to please and not wanting to perhaps look silly or like they don't understand and question something ... so being conscious of that is really important for health professionals.

Many staff said that the health agency environment often exacerbated any underlying hesitancy of service users to interact with health information, which further inhibited inclusive decision making. Most of the participants with intellectual disability said the agency characteristics which supported access and understanding (as described in Chapters 5 and 6), also increased opportunities to appraise and apply information. Fostering friendly,

respectful relationships, flexible appointments, and opportunities to ask questions all affected the willingness of people with intellectual disability to interact with health services.

. Agency cultures and environments often inhibited opportunities for health practitioners to listen and understand what was important to service users. A staff participant experienced in supporting people with intellectual disability to use health services commented:

To me the health world is very directive, they don't do consultation very well they just direct ... people with intellectual disability will just say yes to but is it the right choice for them? ... I think in a lot of situations in health it's just pushed through and support people make decisions for them sadly – because there's that time pressure then there is a lack of information and there is a little bit of acceptance of, that's what the doctor says I should do then I should ...

In a mental health service setting staff identified that anxiety or apprehension associated with past mental ill-health or the stigma of mental ill-health also impeded some people from appraising and applying information. Several staff said that mistrust of staff involved in the admission process impacted service users' willingness to appraise and apply information. These findings resonated with the trauma that informed care literature described in Section 1.2.4. Several staff highlighted the impact for people with intellectual disability, and also acknowledged that this was a consideration for all mental health service users.

A number of participants with intellectual disability said that anxiety or fear impacted their confidence to interact with health services and to use information. Their comments were not specifically made in regard to mental health services, however they have relevance for various health agencies. A participant with intellectual disability said that his fear of

hospitals impacted his ability to consider treatment options which involved a hospital stay.

He stated:

I don't like hospitals they are scary and dark ... They are scary and dark places ...  
there are a lot of sick people and I don't want to catch what they are catching – I  
don't like hospitals they are not my thing.

Several staff said that addressing service users' uncertainty, anxiety or fear was a consideration in communication about a health issue or service. The provision of information could either exacerbate or alleviate fears in its style or presentation, which affected the likelihood that service users would consider a treatment or service. A staff member experienced in supporting people with intellectual disability highlighted that the way staff presented information had a significant impact on service users' ability to listen to health information. The staff member said:

And I think that people are really interested to hear more about their health but  
it has to be not scary ... yep ... scary things make people worried ... even when  
you get told information if you are worried you don't hear anything ... get  
something scary at the beginning you don't hear anything else ...

Staff participants described the significant impact of anxieties or fear on the willingness of service users to consider options or engage in health-related behaviour change. The way that health providers presented information influenced how people with intellectual disability interacted with information and their willingness to consider the options available. Staff gave examples applicable to mental health information and general health procedures.

#### 7.1.2 Support to appraise and apply health information

Many service users appreciated the support of family, carers and staff when appraising and applying health information, particularly in light of the impact of the healthcare context described above. They said their interaction had potential to provide essential support, yet also had potential to usurp opportunities for decision making about health. Health staff raised concerns about the ways in which staff communicated with, and the ways in which family or carers supported people with intellectual disability to make and implement health-related decisions. This section outlines some common findings about the way in which supporters influence the activity of appraising and applying health information.

***Families or carers at appointments:***

There was great variation in the support reported by people with intellectual disability when accessing health services. Many of the participants with intellectual disability discussed health decisions with family or carers and implemented them with little support from others. The experiences of the people with intellectual disability interviewed were quite different from Gail, the only carer interviewed.

Gail was responsible for all aspects of appraising and applying information for her son who made minimal direct communication. She was uncomfortable with her level of responsibility deciphering side effects and supporting psychiatrists in symptom recognition. When discussing her role in managing medication for her son, Gail said: ‘...I’m not 100 per cent comfortable doing it but I have to’. Gail saw that the disability support and healthcare system was often reliant on families or carers to appraise and apply information. She expressed concern for the many people with intellectual disability whose families were not equipped to provide this level of support.

Families or carers were often the primary providers of health information to service users with intellectual disability and had varying levels of responsibility for implementing health-related decisions. For many service users the level of family and carer involvement they preferred differed over time, and according to the type of health information discussed. Participants with intellectual disability emphasised that it was important that service providers negotiate parent/carer involvement at each stage of service provision. For example, Raelene was happy to attend appointments with her GP alone to discuss her asthma, but for a new health concern or specialist appointment she chose to take a friend or family member with her.

People with intellectual disability and some staff said that it was important that health practitioners communicated directly with the person with intellectual disability wherever possible. Some of the people with intellectual disability expressed frustration at the default position of many health workers to bypass them and speak to the person who had accompanied them to the appointment. Several health practitioners interviewed identified their tendency to talk to the family member or carer attending appointments rather than to the person with intellectual disability. Some staff said that accessible information could assist them to address this tendency and this is discussed further in section 7.2.

***Assumptions/preconceptions:***

Some staff participants said that staff and/or family attitudes about the ability or motivation of the person with intellectual disability also impacted the opportunity for them to appraise and apply information at health services. A participant experienced in working with people with intellectual disability spoke about the power of the assumptions of family or carer and

staff. The participant highlighted that the assumption that people with intellectual disability will not make 'good choices' was prevalent at some services, stating that:

Currently the underlying assumption is that they [people with intellectual disability] don't have the ability to make good choices – but actually what they want/think they need is very important.

Some staff participants inferred that staff and family or carers at times made assumptions that people with intellectual disability did not have the capacity to decide, when they may have been able to do so. Others highlighted the tendency of staff and family to protect people with intellectual disability from poor choices by deciding on their behalf. For example, an allied health staff participant working at a generalist mental health Agency said:

See, sometimes what happens is everybody is very benevolent and very paternalistic and they want, they do things for them because they think they [the person with intellectual disability] can't do them for themselves.

Some staff saw that using accessible information modelled an expectation of engagement which was useful to combat patterns of communication which excluded people with intellectual disability.

***Risk aversion:***

Risk aversion, or the desire to protect people from making dangerous or imprudent decisions, was one factor identified by many staff as a determinant of options offered to people with intellectual disability to use information. Staff participants identified that parents of service users with intellectual disability often felt more protective and responsible for their adult child's care than the parents of other mental health service users.

The desire to care or protect was a positive attribute of relationships of support confirmed by all participants, yet many participants also linked this to restricting the options offered to people with intellectual disability. Many staff said that the perceptions of family or carer and staff about what was best for the person with intellectual disability governed choice making.

The complexity of risk and consequences for both the person accessing the mental health service and for people around them was clearly troubling to several staff. An allied health worker at a generalist mental health service said, 'So you have to be able to manage the risk but not be risk-averse'. Staff discussed the quandaries which arose when working with people who understood the information but refused treatment or people who decided on an option that may not be the most convenient or healthy. An allied health staff participant experienced in intellectual disability commented on the dilemma faced when a person with intellectual disability chose not to opt for a recommended treatment or course of action. She highlighted the need for staff to be willing to respect the decisions made by people with intellectual disability. She stated, 'There's a decision to be made so you support people in that decision, but you need to respect the fact that they might say no ...'.

Other staff discussed the concept of impact of individual risk on agency risk. Some staff said that protecting agencies against risk was a key determinant of the options provided in mental health and disability support services. A staff participant experienced in supporting people with intellectual disability commented:

[Group homes] are risk averse and need to cover their butts and keep people safe, which I understand, but they are taking away people's rights?



Some staff reflected that assessing risk was an element of appraising information that staff did not often engage people with intellectual disability about. Yet staff who used easy read said that using accessible tools had assisted them to explain risk and to ascertain whether the person with intellectual disability understood the consequences of their choice. Using easy read to explain concepts and answer questions about risk came at a time cost as this was often a lengthy process which required numerous conversations. Follow up conversations to facilitate this style of appraisal were often not possible within the context of health and disability service practices due to appointment limits and time constraints.

***Practicalities and expediency:***

Some staff participants identified that financial or logistical pressures sometimes restricted the ways that service users with intellectual disability were included in decision making and/or implementation of health-related decisions. Staff gave examples where the exclusionary pressures came from various sources including disability service procedures or staffing, health service structures and family pressures. At times the factors which precipitated exclusion were deliberate and at others, unintended consequences of broader constraints or issues.

For example, a staff member experienced in supporting people with intellectual disability explained about the compromises they make: 'It's often about what makes life easy for staff members at the time 'cause they are busy and have lots to do.'

Many staff expressed concern that the preferences of people with intellectual disability were often unclear or unexplored when appraising information and that this made their opinions easier to put aside when applying these decisions. A participant experienced in supporting people with intellectual disability to access health services commented:

–I think that giving people time to process information is not something the world does very well in any regard I think...[people are] pushed into things that they just don't understand and are almost too scared to ask questions...

The support relationships described in the interviews were often a source of both support and stress. Several staff participants said that at times expedient decisions guided by supporters were unavoidable. However, staff said that it was easier to justify efficient options when staff or family or carer supporters did not have a clear sense of what the person with intellectual disability wanted. Participants who used easy read saw it as one strategy that assisted people with intellectual disability and people who supported them to navigate these complicated interactions. They said easy read was a useful facilitator of conversations to appraise options in various settings and many participants said that easy read could have applications when appraising or applying mental health information. This is explored further in Section 7.2.

## 7.2 Using easy read to appraise and apply mental health information

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Many health staff were uncomfortable with the ways that their agencies engaged people with intellectual disability to appraise and apply health information. On reflection, most staff saw that accessible information, such as easy read, could be used as a strategy to increase the involvement of people with intellectual disability in decision making. Accessible information was not always available at the participating mental health agencies, although many staff identified that it would be valuable to navigate the issues described in 7.1. Staff often found it difficult to know whether the preferences of service users with intellectual disabilities making health-related decisions had been considered and implemented.

Health Agency staff identified that appraising and applying information occurred at various times during service access as well as afterwards. Important opportunities for these processes described by staff were during the service planning phase and when providing information for people with intellectual disability to take home. These two opportunities are explored with a focus on current practice, the ways that easy read was used, and the need for accessible mental health resources.

#### 7.2.1 Planning and decision making

Appraising and applying information while accessing mental health services most often occurred during appointments dedicated to planning and decision making. These opportunities included service entry and exit, and ongoing goal setting throughout an inpatient stay or in therapeutic appointments. All staff identified that they used agency forms and planning proformas to guide planning processes. In addition, many staff provided service users with information about treatment options or health conditions to inform the service user of their options to enable them to appraise information and to develop a treatment or discharge plan. Staff reflected on the suitability of the agency documentation and health information resources they used when working with people with intellectual disability.

#### ***Agency documentation and record keeping***

Many staff identified that mandated forms and record keeping systems about service planning made collaboration with people with intellectual disability difficult. Service entry and exit were important points for appraising information and making plans to apply health-related decisions.

At the health Agencies, service entry and exit often involved mandatory forms and large volumes of text-based information and only a few staff had used easy read to make information more accessible at these times. Staff said that the information provided and the documentation required at the commencement of service was often daunting for service users and did not encourage interaction. Many staff spoke about strategies they employed to tailor information, but often felt bound by the legal or policy requirements of essential forms and they felt they did not have freedom to adapt written information as described in Section 5.3.2. An experienced practitioner working at a generalist mental health Agency was concerned about the inaccessibility of care plans, and how clinicians use them. She commented:

So again it depends on each individual clinician's practice, I would say, but most people who've had this, like most consumers [with intellectual disability], I would say have not seen their care plan, even though they signed it.

Many staff said that they often conducted planning meetings verbally while taking notes on paper or a computer which made collaboration with people with intellectual disability difficult. A manager reflected that at her Agency there was not a lot of opportunity 'for co-production', particularly when using electronic medical records. Like paper versions, mandatory use of electronic records in prescribed formats did not promote engagement of service users in decision making and care planning. Several staff identified that electronic medical records made ongoing goal tracking difficult for staff to collaborate with service users. A staff member working at a generalist mental health service expressed dissatisfaction with the current process. Questioning the opportunity for people with

intellectual disability to participate in accessing information to make decisions and use it, they said:

So it's not just about providing information, but the actual processes around information being accessible to people, to use for their own recovery and their own processes. So we have these care plans and stuff which all our consumers are meant to have a copy of, so, A, are they being provided a copy? B, what is that format? C, how is that updated regularly? D, are there mechanisms for the person to engage their own process around developing their own care plan, holding their care plan, all that stuff, being empowered in that process?

Participants said that more accessible planning and service information would be valuable both to enable more service users to understand mandated information, and to remind staff to engage directly with people with intellectual disability. Staff widely understood that some people with intellectual disability required a high level of support from their family or carer, but also identified that accessible information could facilitate greater engagement. Some staff identified that the complexity of the forms and documentation sometimes precluded the independent involvement of people with intellectual disability who would have preferred to access services without family support.

Many staff highlighted the need for standardised mandated documentation that was easier to understand, as well as tailorable planning tools. When discussing planning services after an inpatient stay a manager commented:

The care plan is written down but it needs somebody else to take charge of it often, which is good and is bad, because I think that you need to empower the person who has the difficulty with the content.

The complexity of care plans limited opportunity for engagement in planning and this impacted the involvement of people with intellectual disability in immediate decision making about goals and priorities, as well as their implementation away from the service. Staff working at mental health Agencies who had previously worked in disability services had additional insight into the shortcomings of current planning processes and the potential for accessible strategies in a mental health service setting. Several staff highlighted the benefit of accessible planning tools when working with people with intellectual disability in other settings, they but had not seen these used in a mental health setting. These participants said that working collaboratively with people with intellectual disability using accessible planning tools often happened in disability services or allied health appointments. Many staff said that the opportunity to support people with intellectual disability to engage in planning or setting goals was underutilised in mental health settings.

Most staff were aware of the importance of information to empower and enable choice by people with intellectual disability to appraise and apply information, but many of them said they lacked access to suitable resources and the skills to do this consistently. Many staff felt that accessible documentation, such as easy read, could facilitate greater application of decisions made at the end of their stay at an inpatient mental health service. An allied health staff member said:

Not every discharge looks exactly the same but just even a simplified version of it would be great from a communication point and that could go up on their wall and they could see this is what we're aiming for.

Staff saw that easy read or accessible information options needed to be as quick to find as standard versions, as outlined in Chapter 5. A staff member at a generalist mental health

service commented that the usefulness of easy read or accessible options depended on 'How we embed this stuff in our care planning'.

At Agency 3, plans were underway to develop forms which are more suitable for service users with intellectual disability and their families or carers to plan service priorities. Some Agency 3 staff used accessible information to provide pre-appointment material. For example, one clinic had developed a simple template with pictures which introduce the practitioner and outline the purpose of the appointment. These templates were also useful to increase the engagement of service users with intellectual disability to appraise information and set this expectation for parents, carers and staff. An Agency 3 staff member saw that a 'tool-kit' of easy read and accessible information such as video-based information would be useful to prepare people with intellectual disability for their visit and encourage them to raise concerns or to ask questions.

Several staff suggested that tailorable planning tools and greater availability of standard or mandated documents would be useful for all service users. Some examples of forms that staff said would be useful in accessible formats were pre-admission surveys, service feedback forms, consent forms, the Mental Health Act and information on rights and responsibilities.

### ***Accessible health and service information***

In addition to mandated agency documentation and planning tools, staff used information about health conditions and services to facilitate appraisal of service options. Most staff had limited accessible information resources to use when explaining health issues or exploring treatment options. One medical practitioner at a mental health service said :

Everything that we have for say our, for lack of a better word, regular consumer isn't really – none of it is appropriate for somebody with an intellectual disability

The findings about how people with intellectual disability appraised health and service options reflected the sporadic use of accessible information at mental health Agencies. At mental health Agencies, the information available in accessible formats was limited and often unrelated to mental health outcomes. Often opportunities to appraise and apply information while accessing inpatient services were only to do with immediate decisions about behaviour, meal times or ward routines, rather than mental health-related education or service planning.

Several staff said that it would be useful to have information about topic areas they frequently discuss in appointments in easy read format. A number of staff said standard accessible information would be helpful to support people with intellectual disability to make decisions about treatment options in order to plan and implement during appointments. An allied health worker at a generalist mental health Agency said:

Yeah, I think there would [be a use for easy read] for some really basic things, like understanding what anxiety is, understanding what depression is. Some of the main sort of coping strategies for depression and anxiety, so your breathing techniques, your relaxation exercises, behavioural activation, how to manage your depression, those sorts of things ... and potentially something about psychosis. I think that would be helpful too because that is something that's quite complex and difficult to sort of understand, so maybe around what psychosis is and helping people make sense of their experiences.



The staff quoted had not considered using easy read to enable people with intellectual disability to appraise and apply mental health information. This situation was common to many mental health agency staff who said that they lacked confidence and knowledge to appraise information with service users with intellectual disability.

#### 7.2.2 Information to take home

Participants with intellectual disability said that having the opportunity to take home written easy read material before or after an appointment, meeting or service visit was very useful. Several participants with intellectual disability said that they valued the opportunity to look at easy read information at home, away from the pressure of a meeting or appointment, either alone or with family and carers. The key findings about the benefits of easy read to take home were about having time to think about information, using easy read as a reminder of what to do, using it with families or carers, and using easy read to give feedback.

##### ***Time to think***

Taking easy read information home gave people time to consider information prior to deciding or expressing an opinion on a subsequent occasion. Agency 4 participants gave examples such as information about a medical procedure, an agenda for a meeting or what to expect at an appointment. A staff member experienced in supporting people with intellectual disability commented:

If someone walks away from an appointment with their support worker and has the information on a piece of paper then at least they can go through it later.

Easy read also enabled people with intellectual disability to ask questions another time, or at the next appointment. Similarly, a staff member experienced in supporting people with intellectual disability highlighted the importance of time to process information for all service users:

I think no matter how good a professional is at explaining something and taking time, even the best GP or specialist, then having the info to take home and refer back to ... I think we all appreciate that information – it's not necessarily accessible to a lot of us but having something to refer back to and it's that processing time too. I'm sure everyone would appreciate easy read health information.

### ***Reminder of what to do and when***

Practitioners mentioned various instances where people with intellectual disability took home information to apply. Staff gave numerous examples of accessible information they had developed with people with intellectual disability to remind them of activities to do at home. These included dietary changes, behaviour charts, relaxation techniques and medication advice.

At all four agencies, participants identified the risks associated with inaccessible medication advice, and the benefits of accessible communication strategies to appraise and apply medication information. Staff from all agencies thought that the information that came with medication was too hard for many people to understand, not just people with intellectual disability, and this included people with cognitive disorders or communication impairments. The dangers associated with the lack of understanding about medication that were raised by staff related to both prescription and non-prescription medication. Issues such as generic brands created confusion, as did changes in medication names and dosage.

Some staff said that often people took medication without a knowledge of what they are taking or why. Several staff said that greater availability of accessible information about medication could help, as people with intellectual disability are often reluctant to question medical recommendations. This tendency was explored in 7.1 and is reflected in the following quote from a staff member experienced in supporting people with intellectual disability:

People just do what their doctor or health professional says but they don't really understand it ... so to me that's a massive thing.

Participants said that accessible information was an essential element to address the inadequate opportunities for people with intellectual disability to engage in decisions about medication. Several staff highlighted the need for clear, accessible information about what medication is for, what the side effects may be and what happens if you miss a dose. The discussion with health service staff indicated that they saw the need for both simplified standardised information as well as tailored individualised advice. For example, a medical practitioner said that people with intellectual disability who experience mental ill-health require dosages or combinations of medication that would be uncommon in the broader population. He saw that this required careful instruction and tailored easy read information.

A participant with intellectual disability spoke about the difference it made to her travel plans when her GP gave tailored advice and explained the impact of time change on her medication schedule:

He [local doctor] writes clear instructions when time zone changes for meds and travel. I would just say I want to go from here to here and put it in a way that I

understand and I can show it to my aunt and she can work out when I've gotta take it.

This service user explained the role of her GP to assist her with travel plans and medication as well as the integral part that her aunt played in this aspect of healthcare, and both these roles were reflected in other interviews. Service users and staff said that many that people, including people with intellectual disability, were often reliant on others for information about medication.

Many staff and service users said that pictures, symbols and few words contained in simple written information helped people to manage their medication. Some people with intellectual disability stated that physical reminders such as clear, easy-to-find reminders on the fridge, Webster packs accompanied by written clear instructions, and written plans for when people were out of the home were also useful. Participants identified that medication information needed to be available in a variety of formats to meet the needs of service users. As presented in Raelene's story,

I manage it [medication] myself but it can be hard ... I know that you can get those little pill boxes that you can put your pills in ... everybody is different.

There were some examples of using easy read as a tool to remind service users of information to apply (apart from medication advice) and these were predominantly at Agency 3. Agency 3 staff used multi-modal information and highlighted practices which engaged service users to learn about their emotional health and to make decisions about treatment options (see Section 5.1). Service users at Agency 3 had varying ability to understand information and make choices, and they used diverse communication modes. Several staff said that the diversity of ability amongst their service users reinforced the

importance of understanding individual needs and preferences in order to tailor information. These staff reported that using a suite of strategies was a platform for service users to engage in appraising health information to apply as needed after the appointment. Staff who worked in a specialised weight management team for people with intellectual disability gave several examples that have application for information about mental health. This team regularly supplied information to people with intellectual disability and their families or carers about nutrition and weight management to appraise at the appointment, and to apply at home. These staff found that they had most success when they worked to explain nutritional information clearly with both the service user and the family or carer, using pictures and relevant examples. The weight management team staff found that tailored accessible, easy read style information was motivating for service users. The staff reported that service users were more likely to adhere to health-related decisions made at the clinic when accessible communication techniques were used.

### ***For family or carers***

Several staff across all Agencies said that accurate and consistent information was important to facilitate appraising and applying health-related decisions away from the health service setting. Many staff highlighted the benefit of accessible communication resources for accurate information for people who were supported by multiple support staff or family members. Service and discharge plans were often the basis for take-home information to guide the implementation of decisions among various supporters and the findings highlight the benefit of using accessible formats.

Agency 4 staff highlighted the benefits of easy read for families and support workers to share health information with people with intellectual disability and with each other.

Several staff discussed scenarios where they were unsure whether the family or carer understood the information discussed at appointments. Staff were concerned as family or carers attending appointments were often responsible for passing information on to the service user with intellectual disability and to other family or carers. A staff member who regularly supported people with intellectual disability said there were many benefits of using easy read to communicate with families or carers. She stated that easy read combats issues which arise when multiple staff with varying literacy levels support the implementation of health-related decisions:

I mean when you talk about literacy levels across Australia that are surprisingly you know quite low ... if you've got a support worker sitting with someone at a doctors and the people with an intellectual disability doesn't understand it but the support worker doesn't either like that's a massive thing so they're the ones that are responsible for taking that info back sharing it say with the group home staff ... if they don't understand it then [they have a problem].

### ***To provide options for feedback***

Several Agency 4 staff gave examples of using easy read to gather feedback from people with intellectual disability, but none of these were at health organisations. Agency 4 participants described occasions when using easy read had increased the confidence of people with intellectual disability to take a course of action, for example in speaking up about an issue or to follow a complaints procedure (see Appendix 21 for further examples). Staff at health agencies said that mandatory feedback opportunities, such as exit surveys,

were often difficult to understand. Several health agency staff were concerned that their agencies did not accurately gather the feedback of people with intellectual disability. Almost all staff were dissatisfied with the accessibility of current options and many expressed frustration as well as an interest in exploring more appropriate alternatives.

### 7.2.3 Benefit of easy read when appraising and applying information

Using pictures and text, such as easy read, to facilitate interaction was not prevalent in the participating mental health services but people who had used easy read strategies saw that there was scope for greater use. Participants familiar with easy read emphasised the benefits of using it to support people with intellectual disability to appraise and apply information. Most of them said that easy read was a communication strategy that they often used in conjunction with other approaches. Flexible or tailored communication options were important when supporting people with intellectual disability to appraise and apply information, just as they were important for understanding information (see Chapter 6). Easy read users identified that the combination of simple text and pictures gave many people with intellectual disability a strategy which facilitated opportunities to discuss issues, ask questions and express opinions.

Several people with intellectual disability and their supporters from Agency 4 used easy read documents as a focal point for interaction and planning in meetings or appointments. Using easy read information benefited both the service user and the provider to facilitate discussion. A staff participant who was experienced in providing support for people with intellectual disability to access health services commented:

It goes both ways – for health professionals as well to understand intellectual disability is just as important as for people with intellectual disability to understanding the information that they have been given.

Another staff member who had worked extensively in roles supporting people with intellectual disability also described how easy read can be used to facilitate conversation. The staff member explained that easy read offers a framework for health practitioners to use when explaining difficult concepts:

Easy read is the framework to explain it to someone with an intellectual disability in a way that they might be able to understand. So it helps the professional to see the way in which they need to explain things. So like if it's written down then they are likely to read it out to them like that ... so I think it takes the professional down from medical language or difficult language to something that is more accessible.

Staff participants emphasised the benefits of both pictures and simplified text when they described how they used easy read to facilitate discussion and information appraisal. The pictures were a useful point of reference which provided a prompt for people who did not read and a talking point for both service users and service providers. Another staff participant said that in a previous workplace, easy read was used to 'Give people with intellectual disability the words,' to express symptoms or side effects when discussing their health. The interviewee said that using easy read introduced concepts and vocabulary which enabled people with intellectual disability to interact about their health more readily.

The staff participants emphasised the importance of conversation and verbal interaction when supporting people with intellectual disability to appraise and apply health information and viewed easy read as a valuable strategy within relationships of support. Easy read



introduced clear, understandable words which enabled greater shared understanding of concepts when communicating medical information. The combination of pictures with accompanying text in easy read provided consistent words and images to represent health concepts across numerous conversations. The consistency in words and images used helped to facilitate appraisal and application of health information with staff, family and carers when required.

Several staff familiar with easy read identified that using accessible information had an additional benefit of conveying that their agency had an expectation that people with intellectual disability were included in engaging with information about their health. Using accessible information conveyed that the agency expected and welcomed interaction, rather than parental or carer engagement as the default. The message or invitation to participate in appraisal and application was useful for people with intellectual disability, their families and practitioners.

#### 7.2.4 Responsibility to provide accessible simplified information

Most staff were eager to have accessible communication resources available, as outlined above, but few had experience in developing or using accessible information to facilitate appraisal and application of information. Only a few participants regularly developed and used easy read. It was this group who provided insight into the difficult process of simplifying information, the dilemmas they encountered and the potential impact on appraisal and application. Several easy read creators said that conveying health information in accessible formats required great consideration and care as the decision to include or exclude certain details had potentially significant consequences on the options available to people with intellectual disability.

Those staff who regularly created accessible information recognised that often, by design, easy read had fewer words and more distinct or direct messages. Staff who discussed this issue highlighted the unintended limitations on information access that occurred when simplifying information. Many Agency 4 staff who regularly simplified information with and for people with intellectual disability conveyed a sense of discomfort as 'gatekeepers' of information. A staff member experienced in creating and using easy read commented on the direct language in health messages tailored for people with intellectual disability:

I've been very conflicted about that in my consultations that I have been running around health about whether I am becoming an agent of social control in the materials – like is this really the person's choice around being healthy or not? ... am I actually facilitating the process to enable them [or] to be more coercive in the way that they get the message across? And these things have been sitting quite uncomfortably with me in doing it.

Another staff member similarly experienced in creating and using easy read asked the question of themselves:

Are you by giving an easy read version of health information, are you denying people of all information?... should you give them the full info as well?

Many staff experienced in developing accessible information recognised that easy read empowered people with intellectual disability to interact with the health system, yet could also inadvertently restrict the choices for appraisal. A staff participant was concerned that decisions about how to enable access were not transparent, as often staff did not reveal how content was prioritised or represented. Easy read creators identified this as an area for agencies to consider when providing or using accessible information such as easy read. The

complexity of simplification and the potential influence of people who decide what to include in accessible formats and what to omit has been noted in the literature (Buell, 2016) and is discussed further in Chapter 8. The potential of supporters to influence the options appraised and applied was a concern for many staff participants. These concerns spanned the activities of creating easy read, using easy read, and facilitating appraising and applying information using other strategies.

All of the staff who raised concerns about the content or tone of easy read emphasised the importance of making accessible information available, despite their reservations. Their concerns were centred upon agency governance over how easy read is made and used, rather than questioning the value of easy read. This group of participants was convinced of the benefits of accessible information to enhance opportunities to appraise and apply information with people with intellectual disability.

### 7.3 Summary of appraising and applying information

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Raelene's experience offers an example of a service user who accessed the information she needed, understood what she accessed, appraised her options for treatment and applied it when required. Her relationship with her GP, her confidence to approach service providers and advocate for an appropriate communication strategy led to the outcome of being able to independently manage her health. The experience of Lara, reported in Chapter 5, who did not have access to information and of Tran, in Chapter 6, who struggled to understand the

information he and his family accessed, illustrated the many factors which influence opportunities for people with intellectual disability to interact with health information. Similarly, this chapter demonstrated that Raelene's experience was contrasted with many people who participated, as service users, service providers, supporters, family and carers. The findings in this chapter illustrated the connection between accessing, understanding, appraising and applying information. The limited availability of accessible information such as easy read, and service structures which precluded flexible practices explored in Chapters 5, 6 and 7, subsequently impacted opportunities to appraise and apply information. Considering appraising and applying information together in this analysis was useful as the activities were difficult to separate in the context of this research. This exploration of appraising and applying information reinforced the importance of the findings about accessing and understanding information. Using Sørensen et al.'s(2012) model demonstrates the risk posed by agency practices which limit access to information and do not support understanding. Such practices jeopardise the right of people with intellectual disability to appraise and apply information.

The findings further underlined the impact of 'social and environmental influences' for people with intellectual disability on the process of appraising and applying health information. The surrounding relationships of support, both within agencies and from family or carers, were crucial for many people with intellectual disability. The flexibility to provide support within appointments, and the availability of accessible information both contributed to the 'readability' or accessibility of agencies. The findings demonstrated the relationship between agency accessibility and opportunities for people with intellectual disability to appraise and apply information.

There were limited opportunities for people with intellectual disability to access, understand, appraise and apply information about mental health. Making accessible information resources such as easy read available is only one element in remedying the problem. System-wide agency commitment is required to support staff to engage people with intellectual disability in appraising and applying health information. The implications of these findings in answering the research questions, addressing the gap in knowledge identified in the literature, and for practice are discussed in Chapter 8.

## CHAPTER 8: THE IMPLICATIONS OF LIMITED ACCESS TO MENTAL HEALTH INFORMATION

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People with intellectual disability value easy read to help them understand, appraise and apply information in various settings, including health services. Despite these benefits, easy read mental health information was not often available to people with intellectual disability. Most staff did not have access to easy read resources and many lacked confidence offering people with intellectual disability opportunities to understand, appraise and apply information about mental health. Mental health policy rarely incorporated communication strategies for working with people with intellectual disability, despite an alignment with the right to information stated in the UNCRPD. Agencies' approach to applying policies about the right to information significantly affected information access for people with intellectual disability, confirming that the context of communication was influential.

This chapter addresses each of the research questions, then examines the contribution of this research to broader scholarship, and goes on to explore the implications for practice.

The chapter concludes by outlining the strengths and weaknesses of the research.

## 8.1 Addressing the research questions

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This research was guided by the overarching question: *How is easy read used to make information about mental health more accessible for people with intellectual disability?*

The incorporation of policy analysis, resource mapping and qualitative interviews across four Australian Agencies generated a complementary array of data to address this research question. This section addresses the overarching research question by outlining the findings in relation to each of the research sub-questions (listed in Section 2.4.1).

8.1.1 How does the current positioning of easy read in policy enable information access within mental health services?

A key finding was that there was limited policy guidance about communication strategies suitable for people with intellectual disability to inform mental health Agency staff. The policy included in the review (Chapter 5) was consistent with Australia's commitment to the rights of people with disability to information, as expressed in the UNCRPD. However, there was a lack of detailed instruction about accessible communication. This finding was consistent with the conclusions reached in related research (Dew et al., 2018), that the needs of people with intellectual disability were not included in Australian mental health policy. Limited policy guidance about communicating with people with intellectual disability was reflected in variations in practice, limited availability of accessible information and calls from staff for clearer direction.

### *Variations in practice*

The limited guidance in policy meant that staff independently decided how and when to make information easier to understand. This resulted in significant variation in practices

within, and between, the participating health Agencies. Factors such as agency culture, workload, administrative demands and staff experience or attitudes tended to determine practice instead of Agency-endorsed principles expressed in policy and processes.

Communication practices at the health Agencies were therefore highly dependent on the commitment, skill and knowledge of individual staff, rather than on Agency obligation.

Governance structures which recognised the obligation to provide accessible information for people with intellectual disability, and process or practices reflective of this commitment, were absent outside of specialised services. The concordance between the values expressed in policy which upheld the right to information and staff practices varied substantially.

#### *Limited accessible communication resources*

This dearth of guidance about communicating with people with intellectual disability across all levels of policy and procedural directives was reflected in the shortage of accessible information resources. The resource mapping demonstrated that there was limited accessible information readily available at Agencies that were not specialised in providing services for people with intellectual disability. Interview findings confirmed that there was no consistent or systematic operationalisation of the policy commitment to making accessible communication resources available. Many staff were aware that they had a responsibility to provide access to information and were troubled by the lack of accessible communication resources available to them. However, a small number of staff viewed information tailored for people with intellectual disability as outside of their Agency's responsibility and beyond the scope of their role.

#### *Clearer directives about communication strategies*



In addition to more accessible communication resources, many staff said that more explicit direction about communicating with people with intellectual disability would be useful. The desire for greater policy direction in communicating with people with intellectual disability expressed by many health staff exposed a broader challenge for policy makers. Some staff recognised the impact of policy on Agency culture and processes, but did not view policy as a source of direction for their own practices. At all health Agencies staff expressed a reluctance to consult policy. Most health staff said that Agency culture and a supportive team were more influential in promoting accessible or inclusive practices than policy in their workplaces. This was true of both specialist intellectual disability health services, who regularly used accessible information, as well as generalist mental health Agencies less familiar with these resources. Most health staff said that policy could be a valuable source of direction if it was easy to find and relevant to their day-to-day practice.

Taken together, findings from the policy analysis, resource mapping and interviews reinforced the vital role of Agencies to foster and support practices which promote information access. The lack of guidance at a policy level is significant as Agency practices, including the availability of accessible communication resources, had a considerable bearing on the experience of people with intellectual disability seeking health information. This confirmed the impact of agency accessibility, or 'readability', in the integrated health literacy framework devised by Sørensen et al.(2012). The connection between agency practices and the skills required by people accessing health services recognised by Sørensen et al. (2012) reinforces the importance of relevant policy to inform agency practices. The interplay between agency processes and information access underscores the value of policy to support staff to facilitate opportunities for people with intellectual disability to interact with health information.

Agency policy and related processes were key in upholding the right of people with intellectual disability to access health information. Current mental health policy did not foster flexible practices, provide adequate guidance about communicating with people with intellectual disability, or position accessible communication resources to facilitate their use. Significant change is required to link the principles outlined in overarching or high-level policy documents with agency processes and staff practice. This is explored in Section 8.3.

#### 8.1.2 How is easy read and accessible information used by staff working with people with intellectual disability in mental health services?

People with intellectual disability often did not have access to mental health information that they could understand at generalist mental health Agencies. On the occasions when mental health agency staff used easy read or accessible information it was primarily to provide information about behaviour management or routines. Accessible information was rarely used to enhance the understanding of people with intellectual disability about their mental health, or to provide opportunities to appraise and apply health or service information. Various factors contributed to the limited use of easy read and accessible information by people with intellectual disability at mental health Agencies. Some of the key factors were: staff attitudes and confidence, the service environment, and limited availability of accessible communication resources.

##### *Staff attitudes and confidence*

Staff attitudes toward the inclusion of people with intellectual disability in their services were mixed, which was reflected in their sense of responsibility to adjust communication. Staff gave candid insight into their attitudes towards inclusive service models and the capacity of their agencies to provide services to people with intellectual disability. Staff

working in specialised intellectual disability settings were confident to use accessible communication resources and inclusive practices. Some staff working in generalist mental health settings recognised everyone's right to generalist mental health services, and this was reflected in their attitude towards accessible information. These staff expressed concern at the limitations they encountered when seeking to provide information to people with intellectual disability. Other staff said that they viewed the services offered by their Agency as inappropriate for people with intellectual disability, so had not considered accessible communication strategies.

Many mental health Agency staff said they lacked confidence to communicate with people with intellectual disability about mental health. Staff from the generalist mental health Agencies said that training in recovery-oriented practice (and other person-centred principles) was valuable, and that the training encouraged individualised support and tailored communication. However, the training lacked specific information about working and communicating with people with intellectual disability. Staff said that they would value training in how to use accessible communication practices and information resources about mental health.

Staff who had worked with people with intellectual disability in previous workplaces or those in specialised intellectual disability support roles were more confident to develop and use accessible communication strategies. Less confident staff called upon more experienced colleagues to advise them when possible, but this practice was frequently an informal arrangement. In generalist Agencies where specialist intellectual disability support staff were employed, other staff valued their input but reported that it was not always available when needed as the support needs outweighed the worker's available hours.

### *Service environment*

Staff stated that the inadequacies of the current mental health service system impacted information access and communication for many service users, including people with intellectual disability. Staff raised issues about the mental health system that were not unique to people with intellectual disability. These reflected systemic issues and the grave concerns raised by the AMA (Australian Medical Association, 2018) described in Chapter 1.

Many staff said that mental health services were reactive, time limited, and risk averse. Staff described the mental health service system as a stressful environment for both staff and service users. This sentiment reflected the literature, particularly in relation to the involuntary inpatient environment (Waldemar et al., 2016). Many participants emphasised that mental health services were difficult to access and recognised that fear or anxiety was an impediment for some people seeking mental health services and information. Such apprehension was at times exacerbated by the mental health service environment, which is reflected in the trauma-informed literature (NSW Mental Health Commission, 2014). The time pressures and resource constraints in the mental health service environment often made it difficult for staff to offer service users tailored communication options, or opportunities to appraise and apply information.

Most mental health staff were aware of their responsibility to provide appropriate information for service users. Staff were accustomed to working with people experiencing episodes of mental illness and were aware of the challenge of associated fluctuations in understanding. These challenges are well documented in the literature (Jorm, 2015b; Waldemar et al., 2016). However, staff found communication in the mental health service environment even more difficult when working with people with intellectual disability who

were experiencing episodes of mental ill-health. Many staff said that they needed more support and training in the impact of fluctuations in mental status on communication with people with intellectual disability, and this need is recognised in the literature (Mason & Scior, 2004).

Communication was especially challenging when the staff and service user with intellectual disability had not previously met. Staff and service users highlighted the importance of having flexibility to establish a relationship and include family and carers to tailor support. Many staff said that they lacked confidence, resources and time to establish the relationships with people with intellectual disability to facilitate effective communication, particularly in the inpatient setting.

#### *Availability of accessible communication resources*

Accessible information options were not consistently available at participating mental health Agencies. Staff used various strategies to support people with intellectual disability to understand information. Many staff in generalist mental health agencies had only seen easy read when a family or carer had supplied it to facilitate communication with a person with intellectual disability. These easy read resources were most often used to maintain routines or as a behaviour management tool. Accessible information for people with intellectual disability about mental health services or treatment was often difficult for staff to make or find.

Several common scenarios discussed by staff across participating Agencies illustrated the impact of limited accessible information, and staff training in how to use them. Some staff provided only standard, general information and felt ill-equipped to provide a more tailored approach. Other staff used additional verbal interactions or created ad-hoc visual resources

to use alongside standard resources, and others created or located accessible versions of relevant information with Agency support. Accessible information about mental health services or conditions was rarely available at the generalist mental health Agencies participating in this study, despite the benefits highlighted by people who used it regularly. Several staff suggested that at times, the difficulty staff experienced in finding and using accessible information impacted service users' willingness ask for accessible communication options. Staff identified that some service users with intellectual disability were reluctant to ask for accessible information, as they were aware that finding accessible information was often time-consuming for health practitioners. Staff said that the often-convoluted process of creating or locating accessible information compounded the stigma of disability for some service users. Staff suggested that routinely having accessible information available alongside standard information options could be beneficial and may lessen the stigma of using easy read information.

Staff working in specialised intellectual disability roles often used accessible communication strategies and identified gaps in the resources available to them. Staff used accessible information regularly, and participants gave many examples of this working effectively. Staff offered people with intellectual disability accessible and easy read style information about various aspects of health, including mental health. The agency routinely provided easy read style maps, directions to services, and information about hospital processes. Staff reported that these resources were useful for alleviating the anxiety of new service users. Staff also used easy read as one of a collection of communication strategies to provide a tailored multi-modal approach for appointments about topics such as anxiety and weight management. Accessible communication resources were widely used by participants at the

specialised service to enhance understanding. However, several staff identified the need for more resources to further broaden the opportunities for people with intellectual disability to engage in appraising and applying health information.

Participants at all agencies emphasised the need to increase opportunities for people with intellectual disability to engage in decision making about health.. An implication of this lack of accessible information was that opportunities for people with intellectual disability to access health information and make decisions were often compromised. Making easy read and other resources available at mental health agencies was one factor among many which impacted these opportunities. These findings illustrated the significant impact of agency practices, confirming Sørensen et al.'s (2012) connection between agency accessibility or 'readability', and access to health information.

#### 8.1.3 How do people with intellectual disability and the people who support them use easy read?

The limited use of easy read about mental health stands in stark contrast to findings about its value to the people who use it. The research participants with intellectual disability reported that they used easy read in many settings and were enthusiastic about its benefits. Similarly, specialised staff were accustomed to using a broad array of accessible communication strategies, including easy read, to discuss health-related issues and found it to be effective. Chapters 6 and 7 illustrated that easy read was useful to support people with intellectual disability to understand, as well as to appraise and apply information. The findings highlighted the importance of using easy read collaboratively to tailor information and illustrated the value of easy read for learning and decision making.

#### *Collaboration to tailor information*

Research participants with intellectual disability said that easy read information was most useful when tailored according to their individual circumstance. Several participants with intellectual disability said that health service providers needed access to varied communication strategies, including easy read, which could be adapted to suit individual needs. These findings expanded upon and reinforced the literature which emphasises the benefits of tailoring information and giving access to a wide range of accessible communication options (Mander, 2016; Kean, 2016). To negotiate access to the most appropriate communication strategies it was important for people with intellectual disability to establish a relationship of trust with the service provider.

People with intellectual disability, their family, carers and staff were all identified as valuable collaborators by people who created and used easy read. Easy read or similar strategies were used in various ways at specialised Agencies to facilitate communication and to build shared understanding between people with intellectual disability, their families or carers, and service providers. This finding reinforces the importance of access to easy read resources, as well as opportunities for interaction and collaboration. Findings about the value of collaborative use of easy read were also reflective of scholars such as Hemsley et al., (2011), Mastebroek et al., (2014), Boardman et al., (2014) and Gratsa et al., (2007), as outlined in Chapters 1 and 2. Using Sørensen et al.'s (2012) framework added to existing knowledge about the communication support offered by families and carers by considering their role in accessing, understanding, appraising and applying information.

#### *Using easy read to learn and make decisions*

People with intellectual disability and participants who supported them cited many instances when easy read information had increased opportunities to engage with



information. Some health staff used easy read during appointments to provide words for shared understanding to facilitate direct communication between people with intellectual disability and service providers. Other people used easy read to ensure consistent messages between care staff or family members to facilitate discussion after appointments. It was significant that most of the examples described by staff in health settings involved using easy read to enhance understanding, rather than to appraise or apply information.

The participants with intellectual disability had used easy read to learn about services, and inform decision making about complex issues, but rarely about health. The research participants with intellectual disability gave many examples of times that they had used easy read to learn about an issue, and to make a decision. Similarly, participants who supported people with intellectual disability said that easy read was a valuable tool to facilitate decision making. Several staff suggested that easy read increased the confidence of people with intellectual disability to appraise options and implement or apply choices. This was reflective of the evidence described in Chapters 1 and 2 in studies such as Ferguson and Murphy (2014) and Hemmings et al. (2013).

Increasing the confidence of people with intellectual disability to engage in planning treatment or services is of great value, particularly in the current service environment and this has been identified as an area worthy of investigation (Chinn, 2014; Chinn, 2019b; Wullink et al., 2009; Frosch and Elwyn, 2014). The need for further exploration is particularly relevant in light of the reluctance of people with intellectual disability to question recommendations from family, carers or staff. Staff expressed concern that often agency efficiencies or family and carer preferences were prioritised over the choices of service users with intellectual disability. This finding corresponds with numerous studies that

conclude that people with intellectual disability are prone to acquiesce when health practitioners or family or carer propose an option or treatment (Mander, 2016; Boardman et al., 2014; Poncelas & Murphy, 2007; Ali et al., 2013). Providing strategies to enable people with intellectual disability to engage in decision making is central in enabling people with intellectual disability to have opportunities to participate in personalised service models.

#### 8.1.4 Addressing the overarching question

Findings from the sub-questions come together to address the overarching question: *How is easy read used to make information about mental health more accessible for people with intellectual disability?*

Easy read or accessible information about mental health is rarely used. The findings of this research evidenced the lack of system-wide implementation of the commitment to providing accessible information about mental health to people with intellectual disability. This lack of systemic commitment stands in contrast to the requirement to adhere to the right to information in the UNCRPD and the principles of accessible information represented in Australian mental health policy. Using the concepts of accessing, understanding, appraising and applying information illuminated the impact of Agency structures, staff practices, and the limited availability of easy read or other accessible information. Current practices frequently result in people with intellectual disability being excluded from critical processes such as appraising and applying information, which are essential for service planning and decision making.

## 8.2 Contribution to the current knowledge base

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This research exposed the limited use of easy read and accessible communication at the participating mental health Agencies. The findings add to knowledge about using easy read in healthcare settings, reinforce the significance of relationships of support, and underscore the obligation of agencies to facilitate information access. The knowledge gained contributes a richer understanding of the 'environmental and situational determinants' or influences of health literacy described by Sørensen et al. (2012). This understanding enhances three key areas of scholarship: using easy read, agency practices, and health literacy.

### 8.2.1 Using easy read

The findings confirm current scholarship and contribute new information about using easy read in a mental health context, adding to the emerging evidence base. This research confirms and adds to knowledge about how the term 'easy read' is used, particularly in the Australian experience. More significantly, this research affirms the importance of supportive relationships for effective communication, recognises the potential for wider use of accessible information about mental health, and highlights the responsibilities of providers who create and use easy read.

The limited availability and use of easy read or other accessible information about mental health at the participating Agencies reinforces the literature outlined in Chapters 1 and 2. This shortage of easy read resources was evident in the resource mapping (Table 10) which illustrated the varied use of accessible information across the participating Agencies. Staff at all Agencies expressed that they would value greater access to accessible communication

resources. These findings confirmed reports such as *Shut Out: the experience of people with disabilities and their families in Australia* (Australian Government, 2009) and *Feeling Down: Improving the mental health of people with learning disabilities* in the UK (Foundation for People with Learning Disabilities, 2014). Both of these reports indicated that mental health information was not readily available in accessible formats and recognised its potential to impact current disparities in service access and outcomes.

It was apparent during the research interviews that the term 'easy read' was not widely used, or able to be consistently defined by participants. Apart from specialist intellectual disability workers and staff who had previously worked in disability services, health staff were unfamiliar with the term 'easy read'. Most relevant scholarly articles about easy read and health relate to the United Kingdom where easy read is more readily available and widely used. This finding reinforced the value of conducting this study in an Australian setting to understand the future potential of a possible greater use of easy read. Similarly, the participants familiar with easy read expressed divergent views about the technical design of easy read documents and terminology to describe accessible information. These findings reflected the confusion surrounding the definition of easy read and accessible information as established in the literature (Sutherland & Isherwood, 2016; Mander, 2016). The confusion is worth noting for future projects, but did not affect the capacity of this research to explore accessible communication practices about mental health.

Using the integrated health literacy framework bypassed issues of terminology and specificities of easy read design to focus on how participants used it in a mental health context. The findings reinforced that easy read is a valuable addition to the suite of options available to health staff, but is insufficient as a stand-alone strategy. This finding

strengthened Mander's (2016) claims and confirmed the value of service providers facilitating tailored communication options, using easy read in a suite of accessible communication strategies. The need for service providers to work collaboratively with service users to tailor strategies and thus establish effective communication was evident, reinforcing the literature (Boardman et al., 2014; Iacono et al., 2014; Hemsley et al., 2012; Hemsley & Balandin, 2014; Buell, 2015; Kean, 2016; Mander, 2015).

One of the most consistent findings about using easy read mental health information, reiterated by participants across all Agencies, was the importance of respectful relationships between service users and providers to facilitate communication. Many participants said that the health environment impacted the confidence of people with intellectual disability to ask questions or challenge advice. The impact of the healthcare context on communication has been established in the literature. Findings echoed the work of scholars such as Mander (2016), Chinn & Homeyard (2017), Chinn (2016a, 2019b) and Buell (2016) who identify the challenges to communication for people with intellectual disability in health service user/provider relationships.

The findings emphasise the importance of understanding more about the impact of the healthcare context on how easy read is used. The data showed that easy read, and other accessible communication strategies, were rarely used to support people with intellectual disability to appraise or apply health information. The tendency to exclude people with intellectual disability from appraisal and application of information was identified by participants at all health Agencies, including staff who used accessible information regularly. This finding demonstrated that opportunities to appraise and apply information are not facilitated by access to communication resources alone, confirming Chinn's (2017, 2019b)

assertions about the impact of the culture of healthcare and service provider relationships. Chinn (2017, 2019), Mander (2016), Ferguson & Murphy (2014) and Buell (2016) argue that people with intellectual disability often have limited opportunities to weigh up risks and make informed decisions about health. Chinn and Rudall (2019) emphasise the need to learn more about engaging people with intellectual disability in health-related decision making and information exchange. In the context of current literature, the knowledge generated in this research further underscores the need for greater understanding of the relationship between mental health agency culture and easy read use.

It would be useful to examine the impact of providing high quality, evidence-based easy read mental health resources on the process and outcomes of health-related conversations. Decision-making is an area in which evidence-based information could be particularly helpful. Staff indicated that health or service options were decided upon according to factors such as the convenience of families or carers or staff. Agency efficiencies or practices, or family preferences, were at times prioritised over the individual needs or choices of people with intellectual disability. This tendency was recognised within practices at participating Agencies and in the community, particularly group home settings. Evidence-based easy read information articulating available options could minimise or expose the influence of factors other than the preferences of the person with intellectual disability. Developing transparent, collaborative processes to guide the creation and use of evidence-based easy read materials warrants further consideration (Chinn, 2016a; Chinn, 2019a).

Many participants emphasised the need for transparency surrounding the quality and trustworthiness of easy read health information. Accessible communication resources such as easy read were needed to guide appointments, outline therapeutic interventions and

establish shared terminology between service users and providers. To do this, accurate evidence-based health information and reliable quality resources are required. To use easy read with confidence, accessible health information needs to be based on quality advice or evidence. There is limited commentary about evidence-based easy read or assessing easy read quality, but this is an emerging area of research interest (Chinn & Homeyard, 2017; Chinn, 2019a).

The provision of information in an increasingly privatised environment also highlights the need to consider the governance structures which oversee these processes. The increasing privatisation of disability and health services has significant implications for the dissemination of information. In both direct, individually funded models, such as the NDIS, and in other privatised health settings, agencies may have a vested interest, financial or otherwise. For example, health practitioners may offer only particular therapeutic options in line with their professional or agency bias in care planning meetings (Mladenov et al., 2015) or agencies may use accessible information as a marketing tool to appear inclusive and thus to gain business rather than offer quality information (Chinn, 2019a, p. 9). The ways that policy and governance structures can monitor adherence to the obligations outlined in the UNCRPD is worth considering, particularly in a forum which was traditionally funded and regulated by state agencies.

This research highlights the ethical responsibilities that come with decisions about the information content in easy read and in other accessible communication formats. These decisions not only relate to the accurate representation of health evidence, but also to the tone of the messaging. Findings reflected evidence that easy read guidelines most often focus on technicalities and design features (Sutherland & Isherwood, 2016; Chinn &

Homeyard, 2017). A significant finding was that easy read development can at times be ad-hoc, and decisions about document content or tone are rarely considered, and this was reflective of emerging research. Chinn (2019a) argues that input from people with intellectual disability in the development of easy read is often related to decisions about design and understandability, but rarely in content-related decisions. Similarly, scholars such as Buell (2015) and Bunning and Buell (2012) have raised concerns about the process of easy read development, and the unintended tone of messages conveyed in simplified documents. Apart from their commentary, little attention has been paid to the decisions surrounding easy read content or the implications of these decisions. These findings underscore the need for systems or standardised processes that promote transparency in easy read development.

The desire expressed by staff and people with disability to use easy read in the future to inform decision making about health underlines the need for accurate, evidence-based messages. The positivity and enthusiasm of all participants who use easy read reflected the message of disability advocates in Australia and internationally. Many users say that easy read is valuable and advocate for more availability despite limited evidence about its use, in Australia and overseas (Chinn & Homeyard, 2017; Sutherland & Isherwood, 2016). This research confirms the sentiment of UK scholars that agency practices and culture significantly impact opportunities for people with intellectual disability to interact with health information. Easy read and other accessible communication strategies are one element among many factors which facilitate information access and inclusion in health-related decision making.



### 8.2.2 Impact of agency practices on information access

This research revealed the potential for easy read and accessible information to aid the inclusion of people with intellectual disability in many aspects of mental healthcare. It also highlighted the potential to compromise the quality of care when accessible information was lacking. Conducting the review of policy alongside resource mapping and interviews exposed the disparity between the inclusive principles mandated by high-level policy, and practices which often failed to meet this requirement. The findings confirmed and enriched the knowledge base by further elucidating the current disparity between rights and practices, exploring the impact of agency culture, and highlighting the potential for greater use of accessible information.

A disconnect between the right to accessible information expressed in policy, and the day-to-day experience of staff and service users providing and using mental health services was evident. This disconnect was demonstrated in findings that individual staff skill and commitment determined the availability of accessible information, rather than clearly defined agency directives that included readily available resources or strategies. Staff did not consider providing accessible information as a core duty, and this was evidenced by the gratitude expressed by several staff toward colleagues who had assisted them to communicate with people with intellectual disability. At generalist Agencies, having accessible communication resources and the skills to use them was a fortunate event, or a matter of chance determined by the prior experience of the staff involved in a given situation. These sentiments emphasised that for many staff, accessible information for people with intellectual disability was a favour or bonus, rather than a right. This positioning

of accessible information resulted in inconsistent availability of information suitable for people with intellectual disability within, and between, mental health services.

This exploration of information access is novel in its focus, buttressing evidence found in related research and reports about access to mental health services. Findings about the inconsistent and limited availability of accessible information to do with mental health are consistent with the literature. Papen and Walters (2008) argued that the health system is difficult to access for people with limited literacy. Similarly, Lincoln (2015) found that in the mental health system people with limited literacy were often precluded from information and therapeutic interventions due to the dependence in this sector on text to convey messages. In the Australian context this research adds new detail about accessible mental health information. It builds upon numerous studies and reports which highlight the shortcomings of mental health services for people with intellectual disability (Australian Government, 2009; Trollor, 2014; Whittle et al., 2018; Weise & Trollor, 2018; Venville et al., 2015). The limited availability and use of accessible information has resulted in scarce opportunities for education about mental health conditions or services for people with intellectual disability.

The limited accessible educational or therapeutic information, and emphasis on information about behaviours or routine, was at times reflective of wider Agency culture. Generalist Agencies did not support, or have capacity to accommodate, varied communication needs. Pressures related to agency goals and efficiencies often compromised service flexibility and staff ability to tailor information to meet individual needs. Prioritisation of efficiencies was reflected in findings about decision making in Chapter 7 and evident in the types of accessible communication resources available (Table 10). At some agencies the only

accessible information used was about behaviour management and routines which reflected a priority on agency routines or prescribed treatment, rather than individual choice. These findings were reminiscent of Goffman (1961) and Wolfensberger's (1972) work explored in Chapter 1. Both scholars emphasised the impact of prioritising agency efficiency over individual choice or need, and particularly the predominance of these practices in congregate care settings.

For some service users, the absence of a systematic application of practices for accessible information resulted in a continuation of exclusionary practices. This is evident in Lara's experience in hospital (Chapter 5) and staff interviews about mental health services. Limited use of accessible mental health resources impeded the ability of staff to include people with intellectual disability in educational or therapeutic activities. Group education and therapy sessions at the mental health Agencies were an example of a core intervention that did not accommodate the needs of people with intellectual disability. People with intellectual disability were not included in therapeutic groups, or offered a suitable alternative at the mental health Agencies. Although group intervention was not a focus of this thesis, accessible communication and adjustment in group activities have been shown to be effective and worthy of further investigation (Douds et al., 2014; Sheehan et al., 2017). The finding about limited access to therapeutic and educational information resonates with recent calls from disability and mental health advocates and researchers for mental health service reform, including greater access to information (Australian Government, 2009; Foundation for People with Learning Disabilities, 2014).

Underlying inadequacies in the mental health service system impacted access to information for people with intellectual disability. The concerns raised by several

participants about the capacity of NSW generalist mental health services to respond to the needs of people with intellectual disability reflected the literature outlined in Chapter 1. Interestingly, participants who worked in mental health services, and participants who made referrals to mental health agencies, raised similar concerns. The problematic history and current barriers for people with intellectual disability who require mental health services, presented by Venville (2015) and Whittle (2018) were reflected in the findings (Chapters 5-7). Findings reinforced the evidence about the continued influence of historic practices and attitudes. The impact of this history was evident in both staff attitudes about their own Agency practices, and in wider concerns about the capacity of current service models to meet the needs of people with intellectual disability.

The benefits of service flexibility and commitment to including families and carers in service provision emphasised in the findings did not negate the need for tailored accessible information. Including family or carers to support communication was of great value to many who found mental health information difficult to understand. However, at times, staff reliance on family members to facilitate communication obscured or compensated for complex agency practices. The reliance by agencies on family or carers to facilitate communication contributed to a decreased sense of responsibility for the service to provide accessible communication resources and training to staff. This reliance reinforced the behaviour of practitioners directing communication to the family member or carer rather than to the individual with intellectual disability. The tendency for practitioners to rely on family or carers, or assume that direct communication with people with intellectual disability is problematic or unworkable has been recognised in the literature (Hemsley et al., 2011; Hemsley et al., 2008; Chinn & Rudall, 2019).

When seeking to address the limited access to mental health information experienced by many people with intellectual disability, a multi-faceted approach is needed. The rushed, reactive culture of many mental health services inhibits rapport building and inclusion of people with intellectual disability in health-related communication. The benefits of a more inclusive culture which encourages collaboration and support was evident in data from all participant groups. The need for flexible practices, in combination with staff training, mirrored the recommendations of recent research and subsequent guidelines (Weise & Trollor, 2018; Department of Developmental Disability Neuropsychiatry, 2014; Agency for Clinical Innovation, 2020; Agency for Clinical Innovation, 2017). The implications for practice are explored in Section 8.3.

#### 8.2.3 Health literacy and intellectual disability

The third contribution to current scholarship arises from using Sørensen et al.'s (2012) health literacy model as a framework for this research. The integrated health literacy framework facilitated greater understanding of how people with intellectual disability use health information. This section explores how this research enriches the health literacy model by exploring the benefits of using a health literacy lens, obligations of service providers, and the central role of relationships to support health literacy.

Using the integrated health literacy framework to scaffold this research demonstrated the interrelated web of influences on health outcomes. This interrelationship was illustrated in three vignettes at the start of the interview data findings chapters (Chapters 5-7). The vignettes showed the multiplicity of factors which influence information access for service users, with intellectual disability as only one of many considerations. The framework and findings were reflective of other research which identifies the array of factors impacting the

health of people with intellectual disability (Hatton & Emerson, 2015). The health literacy model represented the connection between accessible information, individual capabilities, circumstances, and agency practices. Considering these connections moved this research away from a focus on easy read design and its capacity to enhance understanding, which was the emphasis of much easy read research (Sutherland & Isherwood, 2016).

The integrated health literacy framework provided a link between access to information, the right to participate in health-related decisions and the potential impact of these decisions on health outcomes. Findings about appraising and applying information exposed the limited decision making opportunities for people with intellectual disability about mental health. The limited opportunities for people to consider options and make decisions were reflective of the literature (Ferguson & Murphy, 2014; Chinn, 2017; Chinn 2019a).

Considering the activities of appraising and applying information together to illuminate the limited inclusion of people with intellectual disability in decision making was a useful approach in this research, as the concepts were difficult to separate in the data. An analysis of how accessible information is used to appraise information as a distinct activity to applying information could be valuable in research with a different participant group.

The poor health outcomes outlined in Chapter 1 underline the significance of greater understanding about how people with intellectual disability engage with health information, and make and act on health-related decisions. The elements articulated in the integrated health literacy framework augment our understanding of how people with intellectual disability can be supported to have greater access to health information and make decisions about their own health. The interplay between the service context, accessible information

and people with intellectual disability and their families or carers in appraising and applying information was particularly important.

The impact of the health agency context on health communication illustrated the interaction between agency practices and opportunities to access, understand, appraise and apply health information. This relationship is acknowledged briefly by Sørensen et al. (2012) in the framework and encompassed by the concept of agency 'readability'. Sørensen et al. (2012) use the term 'readability' to describe the ease with which service users can access services and information. This research confirmed Sørensen et al.'s (2012) claim that opportunities to access, understand, appraise and apply information were impacted by many factors, often closely related to agency practices, culture or 'readability'. Additionally, by highlighting their responsibility to provide accessible health information as articulated in the UNCRPD, this research has reinforced the pivotal role the agencies should play in enabling access. Defining accessible health information as a right creates an imperative for agencies to make information accessible to service users, and has significant implications for Sørensen et al.'s (2012) concept of agency 'readability'.

Linking the accessibility of agency processes or structures to information access shifts 'readability' from being a choice that agencies may make to improve practice, to a necessity or obligation with significant ramifications. Understanding information access as a right emphasises the responsibility of agencies to provide information in accessible formats, in the context of 'readable' or accessible systems to facilitate access to information. Exposing the disparity between the right to health information and current practices engenders a sense of urgency to address factors which impact agency accessibility. The accessibility or 'readability' of health agencies has potential to influence opportunities for people with

intellectual disability to understand, appraise and apply information. This was found to be so across the information domains of healthcare, disease prevention and health promotion, as defined by Sørensen et al. (2012). This research identified several key service attributes which impacted service accessibility or 'readability' for people with intellectual disability, and these are explored in Section 8.3.

Another finding from this research that enriches the concepts presented in the integrated health literacy framework is the central role of relationships of support for people with intellectual disability. It was in respectful relationships with practitioners and family or carer that people with intellectual disability could engage with health information to make decisions and implement them. These findings provide a practical demonstration of Winance's claim that 'care relationships and dependency underlie autonomy' (Winance, 2016, p. 105). Autonomy is a key aim expressed in the integrated health literacy framework, and these findings confirmed the literature and further illustrate the value of relationships to facilitate autonomy (as discussed in Chapter 1).

The crucial role of support to enable autonomy adds to the understanding presented in Sørensen et al.'s (2012) model in two ways. Firstly, this research underlines the fundamental importance of relationships of support for many people with intellectual disability in accessing, understanding, appraising and applying health information. Sørensen et al.'s model represents relationships of support and care as 'distal' (Sørensen et al. 2012, p.10) to the process of gaining health information. This is represented visually in the placement of relationships at the far-left end of the graphic as 'social and environmental determinants' of health literacy. In contrast, this research has found that for many people with intellectual disability, relationships of care are central to the process of accessing, understanding,



appraising and applying information. Secondly, this research emphasises that while relationships of support with family or carer and agency staff were essential for many people with intellectual disability to interact with health information, these relationships were often changing and at times complex. Sometimes these relationships were complicated by the simultaneous presence of protective and risk elements.

Social and environmental factors such as family relationships and agency practices were dynamic influences which significantly impacted opportunities for people with intellectual disability to interact with health information. A dynamic understanding of these factors as influences rather than *determinants* or causal factors reflects the work of scholars seeking to incorporate multiple domains of support within health literacy models (Batterham et al., 2014; Suri et al., 2016). This research confirmed the work of Papen and Walters who recognise the central role of people who support service users in health literacy and claim that 'health literacy is realised in social practices' (Papen & Walters, 2008). Defining these social and environmental factors as dynamic influences rather than as determinants confirmed the benefit of a nuanced understanding of 'social and environmental determinants' within the integrated health literacy framework described in Chapter 2.

Considering how easy read can be used in each of the elements of Sørensen et al.'s (2012) model builds upon the work of scholars who have explored health literacy for people with intellectual disability or limited literacy (Chinn, 2011; Chinn, 2014; Papen & Walters, 2008). Using Sørensen et al.'s (2012) framework enabled the use of easy read and accessible information to be considered when accessing information, understanding, appraising and applying what was learned. Applying these concepts elucidated the value of accessible information to facilitate each of these activities both for people who use easy read

independently and others who used it with support. Using simple text and pictures within relationships of support, as is common when using easy read or other accessible information, galvanises the move away from a dependence on functional literacy when measuring or seeking to improve health literacy.

## 8.3 Implications for policy and practice

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Enabling information access requires systemic change so that the right to information is reflected in staff attitudes, policy, service agency structures and resource availability. This research demonstrated that principles in policy alone are insufficient to support accessible communication practices in mental health services. These findings underlined the need for a systemic approach to facilitating accessible communication. Accessible communication resources were used most frequently in services when they were positioned as part of everyday business, as a right or requirement, rather than a discretionary or additional service that was difficult to locate or create.

Agencies need to be aware of their obligation to provide access to information and foster accessible practices, including access to information. To meet this obligation, agencies need to support staff to provide people with intellectual disability access to health information, facilitate opportunities to appraise it and support to apply it. The findings have implications for policy, for service providers and for people with intellectual disability.

### 8.3.1 Policy

This research reinforced that people with intellectual disability require diverse communication options to enable them to access, understand, appraise and apply health

information. Agencies have a legal obligation to facilitate access to information and this requires policy support. The inconsistent staff practices found in this research reflected that service providers rarely used policy to inform practice, and that policy did not provide clear guidance about communication obligations and strategies. The challenge for policy makers is to incorporate guidance about accessible communication in policy in a way which reflects the UNCRPD, encourages inclusive attitudes, and is useful to staff. This research demonstrated the need for policy that clearly describes accessible communication strategies, endorses an inclusive culture founded on rights, and encourages greater collaboration in policy development.

More detailed instruction and practical strategies are required to facilitate communication between staff and people with intellectual disability as current policy guidance is insufficient to inform staff practices. The right to information is expressed, but clear communication strategies for staff working with people with intellectual disability are rarely included in instructional policy documentation such as procedures and guidelines (see Section 5.3.3). For policy to be informative for staff, it needs to contain clear instruction, terminology and consistent messages across document types (ie. policy, directives and guidelines). Schalock's (2017) article argues that policy supports rights most effectively if it contains clear, measurable strategies and many staff participants shared this view.

One option for Australia would be to follow the policy example of the United Kingdom (UK), where mandating accessible communication resources has successfully increased the availability of easy read and other accessible information. The UK experience has shown that access to easy read information can be increased through such mandates, but this is not a signifier of understanding or assurance of the opportunity to understand, appraise or

apply information (Mander, 2016; Buell, 2015; Chinn, 2017). Policy mandates for accessible information need to incorporate instruction for staff about how to use these resources, particularly when supporting people with intellectual disability to appraise and apply information. Agency qualities which foster appraising and applying information are embedded in relationships, dependent on staff attitudes as well as agency structures and processes.

To facilitate greater opportunity to appraise and apply information, policy needs to promote inclusion and collaboration across all agency practices. The findings of this research confirm the UK experience that in addition to mandated documentation which enable access, policy needs to incorporate flexible, tailored approaches to support people with intellectual disability to understand, appraise and apply information (Chinn, 2019a; Chinn, 2017). Policy needs to support practices which facilitate and maintain respectful relationships, and clearly define the agency's ethical and legal responsibility to tailor communication articulated in the UNCRPD. The activities or strategies that need to be included in policy to encourage inclusive communication practices differ according to agency type and service focus (discussed further in Section 8.3.3).

Policy would be more likely to be effective if developed in consultation with people who use it, including people with intellectual disability, their family or carer and service providers (Turnbull & Stowe, 2017). One way to support the representation of the needs of people with intellectual disability would be to have greater engagement of people with intellectual disability and people who work with them in mental health policy formulation. Input from services users with intellectual disability would increase the likelihood of the provision of an array of appropriate accessible communication strategies to support access, understanding,

appraising and applying information (Schalock, 2017). Dialogue with staff about the level of detail in documents, practicalities of layout and where policy is housed to suit their needs could increase the likelihood of policy being consulted by staff.

### 8.3.2 Service providers

The most pressing finding for service providers from this research is the mismatch between the rights expressed in policy and the practices described by many study participants. The findings reinforced that a comprehensive approach is required to remedy this mismatch. Agency environment, the availability of accessible information and staff training are all elements that support people with intellectual disability to access, understand, appraise and apply information. These elements are interconnected and need to be driven by a focus on rights and inclusive practices articulated in policy, as described above. The specific implications for service providers will differ by agency type but some common elements can be identified from this research. The implications for service providers relate to agency culture and structures, the availability of accessible information resources and staff training to use them.

Effective communication between staff and people with intellectual disability is most likely in an environment informed by an inclusive agency culture. Approachable staff and a friendly environment were found to foster interaction, whereas a rushed, busy, stressed or reactive environment precluded effective tailored communication. A culture which promotes information and actively encourages the engagement of family or carer is beneficial for both service users and providers. Key enablers of information access included the option to include family or carers, flexible appointment times, locations and formats, and the option to simplify documentation such as mandatory forms/service information.

These findings were aligned with the work of Hemsley et al. who emphasise the importance of flexibility, time and collaboration when seeking to address the needs of people with complex communication needs in hospital (Hemsley et al., 2008; Hemsley et al., 2012; Hemsley & Balandin, 2014).

The vital role of staff to enable access to information highlights the importance of agency processes which support staff to meet this responsibility without administrative barriers or obstructions. Accessible communication resources were most likely to be used when they were familiar to staff and service users, and available at the time they were needed. There is a need for easy read or simplified mandated forms or documents, as well as tailorable health information. These findings add to the limited knowledge base about using easy read in healthcare. UK research emphasises the need for opportunities for interaction when using easy read and using easy read among a suite of strategies to tailor health communication (Mander, 2016; Kean, 2016).

In addition to making accessible communication resources easier for staff to find, training and support for staff in how to use these resources is important. Findings reinforced the literature and advocates who argue that more training is needed to equip mental health practitioners to meet the communication needs of people with intellectual disability (Wullink et al., 2009; Weise & Trollor, 2018). Additionally, increasing staff awareness of existing training and online instruction could be of value as resources are available, but these were not used by staff or agencies. For example, information about how to communicate clearly and develop accessible information is available online (SCOPE and CID). Similarly, resources and guidance about communication in health settings is available from the NSW Health Agency for Clinical Innovation (ACI) website including links to specific

information for staff working with people with intellectual disability accessing mental health services (ACI 2017, 2020). These resources provide varying detail about communication strategies and all reinforce the importance of collaboration to maximise the relevance, engagement and understandability of information. Further training and tailored resources are needed to support staff in a mental health setting and heighten awareness of the supports available.

Findings also underlined the need for training about the right to consider information and the opportunity to appraise and apply information, rather than just the technicality of providing information. Staff attitude significantly impacts information access, illustrating both the importance of respectful relationships to facilitate communication, and the need for staff education about information access as a right (Chinn & Abraham, 2016; Chinn & Rudall, 2019). Staff and agencies have a responsibility to consider the ethics and attitudes that underpin decisions about the content of simplified messages in all interactions, including easy read. More transparent or accountable processes are required as a safeguard against biases in simplified messages, whether these are unintended or otherwise. This is an emerging theme in the literature (Chinn, 2019a), galvanised by the findings of this research.

### 8.3.3 Service users, family and carers

People with intellectual disability will continue to be denied access to information without substantial change to the way communication with people with intellectual disability is facilitated in mental health agencies. The evidence generated from this research highlights the responsibility of health agencies, including mental health, to offer information in accessible formats, such as easy read. The findings could be used, alongside the extensive work of scholars such as Deborah Chinn and Bronwyn Hemsley, to call for increased

availability of accessible information such as easy read and significant changes to culture and practices in healthcare settings. Greater collaboration with people with intellectual disability in policy, staff training, service design, and the development of communication strategies would be a useful starting point for change in mental health services.

## 8.4 Strengths and limitations of this research

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This research used qualitative methodology to explore how people with intellectual disability use and apply easy read information about mental health. The integrated health literacy framework was a valuable scaffold to investigate the ways easy read is used by mental health staff, people with intellectual disability and others who support them. The project design facilitated the consideration of service agencies' responsibility to provide accessible communication resources and the policies which support this, alongside the potential impact of accessible information for individual service users.

A variety of agency types were included in the study. This provided an opportunity to interview participants across diverse areas of expertise. The participants gave insightful commentary on their current use of easy read, and the potential benefits of having more easy read information about mental health available to use. This research generated rich data to progress the understanding of the connection between easy read use and information access in relation to policy, agency processes, and practice. The findings reinforce evidence found in the literature, adding greater detail to this knowledge base, particularly about the Australian experience.



When reflecting on the recruitment process, the enthusiasm and honesty of participants in interviews and the willingness of people to take part was unexpected. Recruitment via established networks in partnership with research supervisors and the university aided this process. It was essential to have people with intellectual disability as part of this research and this group shared great passion and insight for information access. Some staff said that they were motivated to participate to have an opportunity to air the difficulties they faced when seeking to meet the needs of people with intellectual disability. Other staff were unaware of the needs of people with intellectual disability and were willing to share their misgivings and uncertainty. The enthusiasm of participants was a strength of this research. Iterative categorisation worked well with the integrated health literacy framework which provided a scaffold for the large volume of data across interviews, data mapping and policy. Iterative categorisation provided a structured methodical approach that was useful for a relatively inexperienced researcher analysing such a large amount of data. A restriction in this project was the way that people with intellectual disability were included. Greater consultation with people with intellectual disability might have been possible within the timeframe of the research. It could have been beneficial to have used more varied communication options to reach other people with intellectual disability to collect data about their mental health experience. This limitation was managed by including people with intellectual disability who made easy read in Agency 4.

Future research about easy read and mental health could include a more collaborative research approach. Inclusive design is in keeping with the principles which underpin the UNCRPD and upholds the mantra of ‘nothing about us without us’ expressed by advocates of inclusive research and policy development. Inclusion of service users in the design of the

project, data collection tools and, where possible, in assisting with data collection would be valuable to extend the current findings (Bigby et al., 2014; Milner & Frawley, 2019).

A further constraint for this research arose from the limited use of easy read at the participating mental health agencies. The limited availability of accessible resources inhibited resource mapping and detailed analysis of the development and content of easy read documents for use in these settings. Findings about the technicalities of easy read development and use from participants experienced in making easy read resources for other settings included in Appendix 21 are not specific to mental health. The technicalities of developing easy read documents for use in mental health settings is an area worthy of further investigation. Similarly, the use of easy read or simplified language about mental health for people with intellectual disability in phone apps or electronic mediums was not explored , but would be an area worthwhile for future investigation (Sheehan & Hassiotis, 2017).

## CHAPTER 9: MAKING INFORMATION ACCESSIBLE AS A RIGHT NOT A FAVOUR

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This research set out to explore how easy read about mental health was used to make information more accessible for people with intellectual disability. Findings highlighted the benefit of accessible information and illuminated the implications for people with intellectual disability when accessible health information is lacking. This further galvanised the importance of health agencies meeting their obligation to provide accessible information as prescribed by the UNCRPD. Using the integrated health literacy framework (Sørensen et al., 2012) illuminated the connection between easy read, accessible communication, and opportunities for people with intellectual disability to make and implement health-related decisions. The implications of restricted accessible information for people with intellectual disability in the health context were concerning.

Easy read has potential for greater use in mental health agencies. Findings that many participants with intellectual disability found easy read information useful in numerous settings confirmed its value. Easy read was a valuable strategy for people with intellectual disability to facilitate conversation, to act as a prompt for discussion, and to establish a shared understanding of concepts and a common vocabulary. However, most mental health staff were unfamiliar with easy read strategies and adapted information to meet the

communication needs of people with intellectual disability with variable outcomes. The complexity of the mental health agency processes, and of mandated documentation, made the task of simplifying information difficult for staff. Staff working outside of specialised intellectual disability services had limited access to appropriate resources, and many did not feel confident to find or use them. There is a need for greater availability of accessible communication resources, such as easy read, to use in health services.

Easy read or accessible information is vital, but is one of many elements required to make information accessible for people with intellectual disability. Using easy read to facilitate communication is most effective when used in respectful, supportive relationships, with opportunities to ask questions and discuss information. Respectful relationships with service providers was fundamental to all participants with intellectual disability to facilitate communication, and for many the communication strategy used was secondary. The findings elaborate on Sørensen et al.'s (2012) integrated health literacy framework by illuminating the central and dynamic role of relationships of support for people with intellectual disability accessing health information and services. Collaborative relationships between service providers, service users and family or carer, were central to effective communication, yet were often absent in the interactions described by staff working in mental health services.

Many participants were concerned that the culture of health services, including mental health, does not foster relationships to support communication with people with intellectual disability. Service processes, staff attitudes and complex mandated documentation often inhibit opportunities for people with intellectual disability to engage with health information. Agency pressures such as efficiency goals, administrative

requirements and inflexible appointment structures constrained staff seeking to build rapport with people with intellectual disability, and their families or carers. Many participants expressed concern that generalist mental health agencies are ill-equipped to meet the communication needs of people with intellectual disability.

The issues that several participants identified about mental health agencies were reflective of a broader culture which does not prioritise inclusion of people with intellectual disability in health communication. Some participants expressed concern at the limited involvement of people with intellectual disability in health-related decision making. Several staff highlighted that in current service models the preferences of people with intellectual disability are often not elicited or considered when planning health interventions. The limited availability of accessible information such as easy read reflects a broader culture which did not prioritise access to information. A consequence of this lack of commitment to information access is that people with intellectual disability do not have opportunities to make and implement health-related decisions.

The participants made it clear that the right to health information articulated by the World Health Organisation and UNCRPD does not reflect their experience. This was evident in both the experiences of people with intellectual disability accessing information and mental health Agency staff who supported access. Staff expressed much goodwill, yet many despaired at the limited support they are able to provide people with intellectual disability accessing information at their services. The continued disparities in health outcomes between people with intellectual disability and the broader population underscore the significance of continuing to investigate the role that easy read can play in improving information access and outcomes. These disparities provide impetus for further study and a

sense of urgency, as the right to information is the platform for many health-related decisions and the foundation for other rights to be realised.

The disparity between high-level policy commitment to information access and experience at a practice level requires urgent consideration and remedy. Several strategies were identified that could support staff to make information accessible to people with intellectual disability. These included access to appropriate resources, ongoing training and mentoring, as well as governance structures which embed accessible practices within routine processes. Staff and people with intellectual disability highlighted the need for flexible agency structures which support and facilitate relationships and collaboration. The systemic changes required to enable access to information for people with intellectual disability have implications for policy makers, managers and frontline staff. Consultation with and between policy makers, staff and service users is essential to develop systems which support more consistent mental health information access for people with intellectual disability.

Further research about using easy read in a health context is required to facilitate systemic change. The limited availability of easy read in mental health services, despite its wider availability in other service domains, demonstrated this need. Understanding more about how accessible communication strategies, such as easy read, can be incorporated into the day-to-day practice at health organisations would be beneficial. The integrated health literacy framework (Sørensen et al. 2012) illustrated the multiplicity of factors that impact opportunities to access, understand, appraise and apply information. More evidence is needed about how easy read mental health information can be used and supported by Agency structures, particularly to facilitate appraisal and application of health information.

An investigation of the ways that agencies can develop and implement policy that fosters an inclusive culture, supports staff training, and encourages innovation, is vital.

Increasing the availability of easy read strategies and supporting governance structures will be fruitless unless they are accompanied by a shift in agency culture to reflect the UNCRPD. Substantial change is required in the Australian mental health service landscape for people with intellectual disability to have access to information that they can understand. Agencies need to treat the provision of information for people with intellectual disability needs as a non-negotiable right rather than a favour, kind deed or valuable addition to service only when time permits. The challenge for mental health service agencies presented by this research is to recognise their obligation to meet the communication needs of all service users, including people with intellectual disability. Until this right is understood by agencies and reflected in their policy it is difficult to see how staff will be supported to provide information suitable for people with intellectual disability. The obligation to provide health information and its potential to impact health outcomes is clear:

Understanding health as a human right creates a legal obligation on states to ensure access to timely, acceptable, and affordable healthcare of appropriate quality as well as to providing for the underlying determinants of health, such as safe and potable water, sanitation, food, housing, health-related information and education, and gender equality

World Health Organisation (2017).

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## Appendix 1: Agency briefing information

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### **NSW Health Staff Briefing**

#### **Meeting Agenda:**

The following subject areas were incorporated into NSW Health Agency staff briefing. This information was tailored to suit agency type and meeting timeframes.

1. Introduction
2. Project Background – summary of literature review and issues illuminated
3. Project Summary – outline of the data collection being undertaken in the project
4. Agency Involvement & timeframe
5. Participant Information Sheets (PIS) & consent forms – introduce content of PIS for agency staff and service users and distribute for perusal.

All versions of PIS and consent will be provided and issues surrounding recruitment and potential issues regarding coercion/inadvertent pressure to participate in agency and service user relationships will be canvassed.

6. Question time
7. Invitation to participate and provide contact details

## Appendix 2: Interview participant characteristics

Table 12: Interview participant characteristics

Agency		Length of interview (in minutes)	Role	time in position	Experienced working with people with
AGENCY 1	1	24	Medical practitioner (Specialist intellectual disability consultant)	3 months	Yes
	2	*	Medical practitioner (Specialist intellectual disability consultant)	1 month	Yes
	3	29	Manager (nursing)	15 years	No
	4	*	Manager (nursing)	6 years	No
	5	23	Allied Health	18 months	No
	6	25	Allied Health	11-12 years	No
	7	20	Manager (nursing)	6-7 years	No
	8	31	Allied Health	18 months	Yes
AGENCY 2	9	33	other	19 months	limited
	10	52	Allied Health (Specialist Intellectual disability consultant)	18 months	Yes
	11	42	Manager - OT	16 months	No
	12	15	Manager (nursing)	4.5 years	limited
	13	9	Manager (nursing)	3 months	limited
	14	35	Allied Health	-----	yes
	15	44	Medical practitioner	3 years	limited
	16	42	Allied Health	30? years	Yes
	17	29	Allied Health	3 months	No
	18	20	Allied Health	2 years	No
	19	*	Allied Health	2 months	No
	20	*	Allied Health	2 months	No
	21	9	manager	3.5 years	No
AGENCY 3	22	44	Medical practitioner	6 months	Yes
	23	20	Medical practitioner	5 months	Yes
	24	30	parent/carer	10 years	Yes
	25	48	Allied Health	9 months	Yes
	26	*	Allied Health	6 months	Yes
	27		nursing	6 years	Yes
	28		other	-----	Yes
	29	*	other	-----	Yes



	30	19	Allied Health	7 years	Yes
	31	30	Allied Health	2 years	Yes
	32	16	manager	8 years	Yes
	33	33	Allied Health	5 months	Yes
	34	20	Allied Health	8 years	Yes
	35	32	Allied Health	14 years	Yes
	36	48	Allied Health	2 years	Yes
	37	56	Medical practitioner	10 years	Yes
AGENCY 4	38	24	service user	9 years	Yes
	39	24	service user	-----	Yes
	40	*	advocacy & support	-----	Yes
	41	14	service user	10 years	Yes
	42	27	service user	6 months	Yes
	43	8	service user	Couple of years	Yes
	44	31	service user	-----	Yes
	45	26	service user	1 year	Yes
	46	47	advocacy & support	4 months	Yes
	47	51	manager	18 months	Yes
	48	53	advocacy & support	2 years	Yes
	49	47	advocacy & support	2 years	Yes

#### NOTES:

Total of 1230 minutes of recordings – average interview time was 30.75, longest 56 and shortest 9, mean 29.7

\*In interview length indicates staff participant chose to be interviewed with fellow worker/s from their agency.

‘-----’ in time at agency indicates that answer was not provided.

#### Definitions (from list of Terms used p. 12)

Participants have been grouped in the following role categories to retain anonymity:

Advocacy and support: staff whose primary responsibility was to support people with intellectual disability to access services.

Allied health: includes psychologists, social workers, dieticians, occupational therapists, youth workers and exercise physiologists.

Manager: includes service managers unless a separate discipline was identified. For example, Nursing manager.

Medical practitioners: includes psychiatrists, psychiatry registrars, paediatricians and paediatric registrars.

Nursing: registered nurses in roles at inpatient and community-based agencies. The participants had varying experience working with people with intellectual disability. Some had been trained in mental health nursing overseas and in Australia, others had not completed any specialised mental health training.

Other: includes admin staff, evaluation staff and peer support staff.

Service users: people with intellectual disability who used Agency 4 services.

Specialist intellectual disability consultant: staff member employed to provide support to staff working with people with intellectual disability.

## Appendix 3: Summary of policy analysed

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**Table 13: Commonwealth policy documents**

Commonwealth Documents	Year
COAG National disability agreement	2009
Disability Discrimination Act	1992
Disability Services Act	1986
eMental Health Plan	2012
Fed Dept. Health Roadmap for National Mental Health Reform (COAG)	2012-2022
Fifth National Mental Health Plan	2017
Health Disability Strategy	2010-2020
Male Health Plan: Building on the strengths of Australian males	2010
Mental health statement of rights and responsibilities	2012
National Aboriginal & Torres Strait Islander Suicide Prevention Strategy	2013
National Aboriginal and Torres Strait Islander Health Plan 2013-2023	2013-23
National Disability Insurance Scheme Act	2013 (amended 2016)
National Disability Service Standards	2013
National Drug Strategy	2010-2015
National Mental Health Policy	2008
National women's Health Policy	2010
Report of the National Review of Mental Health Programs and Services	2014
The Living Is For Everyone (LIFE) Framework	2007

**Table 14: NSW policy: plans and strategies**

<b>NSW Policy: Plans and strategies</b>	<b>Year</b>
Health Plan towards 2021	2014
Memorandum of Understanding between ADHC and NSW Health	2010
Male health plan	2009-12 (listed as active)
Mental Health Act No. 8	2007 (amended 31/8/15)
Mental Health Commission Act	2012
NSW Dept. Health Aboriginal Health Plan 2013-2023	2012
NSW Dept. Health Aboriginal Mental Health and Well Being Policy 2006-2010	2012
NSW Dept. Health Living Well Mental Health Policy 2014-2024	2014
NSW Health Disability Inclusion Action Plan	2016-2019
NSW Older People's Mental Health Services SERVICE PLAN 2017-2027	2017
NSW school-link Strategic Action Plan 2014-2017	2015
Safe start Policy and Guidelines	2010
Women's health plan	2009-11 (listed as active)
Youth Health Policy	2017-2024

**Table 15: NSW policy: directives and guidelines**

<b>NSW Policy directives and guidelines</b>	<b>Doc type</b>	<b>year</b>
Aggression, Seclusion & Restraint in Mental Health Facilities - Guideline Focused Upon Older People	guideline	2012
Aggression, Seclusion & Restraint in Mental Health Facilities in NSW	Policy	2012
Call Handling Guidelines for Mental Health Telephone Triage Services	guideline	2012
Chief Psychiatrist Panel Review of Complex Mental Health Treatment Plans (policy)	Policy	2011
Children and Adolescents - Safety and Security in NSW Acute Health Facilities (policy)	Policy	2010
Children and Adolescents with Mental Health Problems Requiring Inpatient Care (policy)	Policy	2011
Clinical care of people who may be suicidal (policy)	Policy	2016
Engagement and Observation in Mental Health Inpatient Units (policy)	Policy	2017
Forensic Mental Health Services (policy)	Policy	2012
Management of patients with Acute Severe Behavioural Disturbance in Emergency Departments	guideline	2015
Mental Health Triage Policy	Policy	2012
NSW SMHSOP Acute Inpatient Unit Model of Care Guideline	guideline	2016
Principles for Safe Management of Disturbed and/or Aggressive Behaviour and the Use of Restraint (not in MH facilities)	policy	2015
Psychiatric Emergency Care Centre Model of Care Guideline	guideline	2015
Sexual Safety - Responsibilities and Minimum Requirements for Mental Health Services	Policy	2013
Sexual Safety of Mental Health Consumers Guidelines	guideline	2013
Transfer of Care from Mental Health Inpatient Services	Policy	2016

**Table 16: LHD policy documents**

AGENCY 1		AGENCY 2		AGENCY 3	
<i>Number</i>	Description	Number	Description	Number	Description
1.1	discharge and peer support	2.1	clinical risk and assessment	3.1	admission procedures
1.2	community visits	2.2	emergency sedation	3.2	fact sheet development
1.3	communication	2.3	patient care levels	3.3	care guidelines for people with cooccurring intellectual disability and mental ill-health
1.4	committee representation	2.4	patient leave from acute care	3.4	psychiatric patient transfer
		2.5	identify and respond to domestic violence	3.5	rights and responsibilities
		2.6	extended seclusion and governance		
		2.7	committee representation		
		2.8	telephone support		

## Appendix 4: Policy analysis search terms

The search terms correspond with the rights outlined in the UNCRPD with an emphasis on information access. The search terms devised to represent these three rights presented in the UNCRPD and terms related to easy read:

ACCESS TO INFORMATION	language (with synonyms), accessible language proximity, information, accessible (with stemmed words <sup>2</sup> ) accessible information proximity, accessible information, literacy, communicat*, accessible communication proximity
COMMUNICATION /UNDERSTANDING	understand* comprehend (with stemmed words) ,collaborat* autonom* speak (with stemmed words) talk (with stemmed words)
DECISION MAKING	choice (with stemmed words), decision (with stemmed words), Decision making (with stemmed words), self,self-directed, self-manage, centred, person centred, client centred, consider, options, participation (with stemmed words)
EASY READ	Easy-read Easy to Read Easy English plain English assistive technology adapted language accessible information

<sup>2</sup> Stemmed words denotes that various forms of the word were included in the search, i.e. 'accessible' would also include words such as accessibility.

## Appendix 5: Policy analysis sample spreadsheet

This is a sample from the spreadsheet used to record results of the NVivo search of policy documents. The spreadsheet was used to record the frequency of words and key concepts within documents as a summary to guide analysis. A summary page was created for each policy type as evident in tabs at the bottom of the screen capture.

Document ID	Document	ID mentioned	Easy-read	Easy to Read	Easy English	plain English	accessible information	assistive technology	adapted language	total	language (with synonyms)	information	accessible (with stem words)	accessible language proximity	accessible information proximity	literacy	communicat*	accessible communication proximity	total	understand*	comprehend (with stem)	speak (stemmed words)	talk (stemmed words)	collaborat*	autonom*	total	choice (with stemmed words)	decision (with stemmed words)	Decision making (with stemmed words)	self directed	self managed	centred	person centred	client centred	consider	options	participation ( with stemmed words)	total	
C7	Fed Dpt Health Roadmap for National Mental H	Yes	0	0	0	0	na	0	na	0	2	15	28	0	0	2	2	0	49	9	0	1	1	6	0	17	1	5	0	6	0	0	9	0	1	0	16	47	
C8	Mental health statement of rights and responsi	yes	0	0	0	0	na	0	0	0	5	19	16	0	0	0	4	0	44	2	1	3	0	0	0	6	0	14	0	0	0	0	0	na	na	5	3	14	36
C9	National Aboriginal & Torres Strait Islander Suic	No	0	0	0	0	2	0	0	2	9	25	27	0	2	0	3	0	66	6	0	0	0	9	0	15	1	2	2	34	0	0	0	na	na	0	7	16	62
C10	Report of the National Review of Mental Health	Yes	0	0	0	0	1	0	0	1	6	56	122	0	1	1	13	0	199	9	0	1	1	11	0	22	6	20	5	35	1	0	20	18	0	10	22	34	171
C11	Building on the strengths of australian males	no	0	0	0	0	na	0	0	0	4	23	23	0	0	8	2	0	60	5	0	1	0	2	0	8	2	0	na	8	0	0	0	na	na	9	0	12	31
C12	National women's Health Policy	no	0	0	0	0	0	0	0	0	12	51	101	1	1	11	8	0	185	23	1	4	4	15	1	48	15	21	13	17	1	0	1	na	na	17	6	40	131
C13	National Drug Strategy	no	0	0	0	0	na	0	na	0	0	29	18	na	1	1	4	0	53	5	0	0	0	7	0	12	2	0	na	2	0	0	0	0	0	5	1	9	19
C15	National Aboriginal and Torres Strait Islander H	yes	0	0	0	0	na	0	0	0	12	18	51	0	0	7	2	0	90	8	0	0	1	10	1	20	9	8	6	13	0	0	2	1	0	3	5	27	74
CD1	NDIS act	yes	0	0	0	0	na	0	0	0	2	105	28	0	0	0	6	0	141	1	0	0	0	0	0	1	11	55	5	4	0	0	0	na	na	10	0	219	304
CD2	Health Disability Strategy	yes	0	0	0	0	1	0	0	1	2	26	68	0	3	2	13	2	116	6	0	2	0	8	1	17	10	7	3	5	2	1	6	6	0	8	7	59	114
CD3	National Disability Service Standards 2013	no	0	0	1	0	3	0	0	4	4	18	23	0	3	0	6	0	54	5	0	2	0	5	2	14	12	9	5	4	0	0	7	7	0	0	7	14	65
CD4	national agreement		0	0	0	0	0	0	0	0	0	1	2	0	0	0	0	3	0	0	0	0	0	0	0	3	2	1	1	1	0	1	1	0	1	1	5	17	
CSF	fifth national health and suicide prevention play	yes	0	0	0	0	0	0	0	0	1	42	37	0	0	1	3	0	84	16	0	1	1	15	0	33	3	10	0	25	0	0	9	8	0	1	4	17	77



## Appendix 6: Policy analysis Template I

DOC NUMBER:

NAME:

### Accessible information Policy Content:

*RQ How does the current positioning of 'easy read' in policy and service provision practice enable information access?*

Question	Y/N/maybe	comment
<p><b>ACCESS as a concept:</b></p> <p>Does the policy explicitly mention providing tailored communication for service users?</p>		
<p>Are words such as easy read, accessible communication, easy English used?</p> <p><i>Easy-read      Easy to Read      Easy English</i>  <i>plain English      language</i>  <i>accessible language, adapted language, information, accessible, accessible information, literacy, communicat*, assistive technology</i></p>		
<p>Understanding information - how is this presented</p> <p><i>understand*      comprehen*</i></p>		
<p>Are the concepts of information in order to appraise and apply included in document?</p> <p><i>collaborat*      autonom*      choice, decision, Decision making, self, self directed, self managed, centred, person centred, client centred, consider, speak, talk, participation, options</i></p>		
<p>Concepts from UNCRPD - Rights/inclusion</p>		
<p>Any reflection on tone re. communication?</p>		
<p><i>How does the current positioning of 'easy read' in policy and service provision practice enable information access?</i></p>		

## Appendix 7: Policy analysis Template II

Intellectual Disability Mental Health Policy analysis developed by Dew et al. (2018)

### Policy Document Analysis:

<b>ACTORS</b>	<b>CONTEXT</b>	<b>PROCESSES</b>	<b>CONTENT</b>
Who was involved in formulating the policy document?		How was the policy issue identified?	What is included in the policy document?
		What was the impetus for developing and implementing change?	To what extent and in what ways is intellectual disability included in the content?
Were people with intellectual disability, their carers, people who work with them, represented?	Is the policy in line with best practice and human rights principles? Is the UNCRPD and/or underlying rights principles referred to?	To what extent does policy conform with the values, principles and objectives specified in the UN Convention?	
			To what extent are the strategies outlined for people with intellectual disability linked to clear, measurable actions or targets?
			What is the plan for translating the policy into accessible services for people with intellectual disability?

## Appendix 8: Interview question guide – Service providers

### HOW IS EASY READ USED MAKE INFORMATION ABOUT MENTAL HEALTH MORE ACCESSIBLE FOR PEOPLE WITH INTELLECTUAL DISABILITY?

QUESTION GUIDE FOR SERVICE PROVIDERS		
1. What is your primary role at [SERVICE]? How long have you worked at [SERVICE]?		
2. Do you work directly with people who have intellectual disability and their families?		
3. In your experience, what are the most important factors in making information understandable for someone with intellectual disability? <i>(explore themes as they arise - tailored information, family carer, awareness of power differential)</i>		
4. I am interested to hear how this relates to conveying health information? <i>(explore particular considerations for people with intellectual disability who experience mental ill-health)</i>		
5. Are you familiar with the term 'easy read'?		
	YES (5a-5d)	NO (5e-5h)
	a. At your agency what constitutes an 'easy read' document?	e. Show an example
	b. Where do you access these documents? If they produce their own ... what guides the layout and design?	f. Is this something you use?
	c. How do you use 'easy read'? <i>(give to person with intellectual disability, read through it /facilitation of information appraisal - exploration of options?)</i>	g. What kinds of techniques/tools do you use to enable access to information?
	d. What kinds of subjects are covered in 'easy read' format? <i>(e.g. tailored health info, service guides?)</i> <i>Have you had experience in providing information about mental health in an 'easy read' format?</i>	h. How do these techniques/tools enhance understanding?
6. Are there other things that you see your agency does well to make information for people with intellectual disability i) available? And ii) understandable? <i>And Not so well?</i>		
7. I am also interested in the way that accessible information provides opportunity for people with intellectual disability to explore options for service or treatment - are there ways that your service encourages this? <i>(Explore appraise/apply in relation to agency role, link to strategies discussed in previous questions)</i>		
8. How do you see that the policy and procedures that govern the work at CID impacts information accessibility?		
9. Is there anything else about making information accessible for people with intellectual disability that you would like to share?		

## Appendix 9: Interview question guide - Service users

### HOW IS EASY READ USED TO MAKE INFORMATION ABOUT MENTAL HEALTH MORE ACCESSIBLE FOR PEOPLE WITH INTELLECTUAL DISABILITY?

The language for each question has not yet been established as it will be dependent on the needs of the individual and tone of the interview. The questions schedule is designed to be as flexible as possible so as to allow the interviews to be steered by participants.

The interview will commence with confirmation of consent/general introductions to one another and the aims of the project, housekeeping and warm-up questions.

SERVICE USER QUESTION GUIDE (people with intellectual disability and their carers)		
How do you come to see at [SERVICE]		
How often do you see them?		
When did you first come?		
What do you usually do when you come to [SERVICE]?		
Do you usually bring [CARER] with you, or come alone?		
I would like to learn more about the ways that you get information - I am especially interested in information about health. How do you usually find out about health or health services? <i>(prompt if needed: Can you tell me about a 'health appointment' or whatever they describe as where they get information ... if it went well?)</i>		
When someone is telling you something important or giving you information, how do you like them to tell you? Words, on paper? Are you the kind of person who likes to ask questions and talk about different things? <i>(explore role of family or carer and opportunity to appraise information)</i>		
Do you ever talk to anyone or get information about 'mental health'? <i>(explore – maybe it's talking about how you are feeling or your worries?)</i> Have you ever been given information about these kinds of things? Can you tell me about that?		
Have you heard of 'easy read'?		
	YES	NO
	Show an example – is this what you think of? If no, what?	Show an example
	Where have you seen 'easy read'?	Is this something you have ever seen used?
	How did you use 'easy read'? <i>(given to carer, read through it at Dr, took it home)</i>	Do you think it would be useful? What for?
	What was the 'easy read' about? <i>(e.g. tailored health info, service guides?)</i>	Relate to previous discussion – how they access, understand information, clarify
I'm planning to write a report that will go to places like doctors and hospitals/people who decide how information is given out or talked about – so I want to know if there is anything you would like to say to them. So I want to ask: What is the most important thing for people to do when they give you information about your health or being healthy? <i>(re-phrase &amp; prompt to focus on mental health if appropriate)</i>		
Undisclosed in interview) Just as we finish would you mind if I ask for your ... Postcode		

Age range 18-25, 25-35, 35-45, 45-55, 55 +

Living arrangements – independent, family, group home style accommodation

Service usage history

## Appendix 10: Participant information statement and consent (staff)

NOTE: this is an example only. Logos and contact details differed at health sites

	
<b>PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM</b>	
Agency Staff <b>Easy Read information for people with intellectual disability</b> Professor Julian Trollor	

### Easy Read information for people with intellectual disability Research Project

#### 1. What is the research study about?

You are invited to take part in this research study. The research study aims to explore how Easy Read is used to make information more accessible. We are especially interested in how people with intellectual disability access information about health. You have been invited because your agency works with people with intellectual disability and uses Easy Read.

#### 2. Who is conducting this research?

The study is being carried out by the following researchers:			
Role	Name	Organisation	Telephone
Chief Investigator	Prof. Julian Trollor	Department of Developmental Disability Neuropsychiatry (3DN)	(02) 9931 9160
Co-Investigators	Prof. Karen Fisher	Social Policy Research Centre, UNSW Australia	(02) 9385-7800
Student Researcher	Bronwyn Newman	Social Policy Research Centre, UNSW Australia	(02) 9931 9160
Research Funder	This research is funded by the National Health and Medical Research Council		

#### 3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who work as managers or direct service providers at NSW CID.

#### 4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

**5. What does participation in this research require, and are there any risks involved?**

If you decide to take part in the research study, you will be asked to participate in a face to face interview. The interview will take place at NSW CID at a time that is convenient to you. You will be asked questions about how people with intellectual disability get information about health. It should take up to an hour to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. This audio tape will be transcribed by the researcher, Bronwyn Newman and stored on a secure server at UNSW. If you would like to participate but do not wish to be audio recorded, please let the researcher know and we can discuss other options, such as taking written notes.

We don't expect the questions to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance. If you would prefer to speak to someone not involved in the project please see the numbers listed below.

**6. What are the possible benefits to participation?**

We hope to use information we get from this research study to guide services who provide health information to people with intellectual disability.

**7. What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your identifiable information, such as consent forms and audio recording, will be stored securely at the university and destroyed after 7 years.

We will store information about you at UNSW in a format that does not identify you or your agency.

Researchers at UNSW are required to store their anonymized data in the UNSW data storage system, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your identity will not be identifiable.

Your information will only be used for a research report and to share general findings with service providers and policy makers. The information collected for this research project will be made available to others in a way that participants cannot be identified.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

**8. How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by adding your email or postal address to the consent form. We will only use these details to send you the results of the research.

**9. What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or NSW CID.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

**10. What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

<b>Name</b>	Bronwyn Newman
<b>Position</b>	PhD student
<b>Telephone</b>	(02) 9931 9160
<b>Email</b>	<a href="mailto:Bronwyn.newman@student.unsw.edu.au">Bronwyn.newman@student.unsw.edu.au</a>

**Support Services Contact Details**

If at any stage during the study you become distressed or require additional support from someone not involved in the research please call:

<b>Name/Organisation</b>	Mental Health Line
<b>Position</b>	The Mental Health Line is a 24-hour telephone service operating seven days a week across NSW. It provides connections to crisis support and counselling.
<b>Telephone</b>	1800 011 511

**What if I have a complaint or any concerns about the research study?**

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

**Complaints Contact**

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+ 61 2 9385 6222
<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>HC Reference Number</b>	<b>17146</b>



## Appendix 11: Participant information and consent (service users)

NOTE: this is an example only. Logos and contact details differed at health sites



### 1. What is the research study about?

You are invited to take part in this research study. The research study aims to explore how Easy Read is used to make information more accessible. We are especially interested in how people with intellectual disability access information about health. We would like to speak to people with intellectual disability, and would be happy to include a friend, carer or other trusted person in the interview if the person with intellectual disability chooses to do so.

### 2. Who is conducting this research?

The study is being carried out by the following researchers:			
Role	Name	Organisation	Telephone
Chief Investigator	Prof. Julian Trollor	Department of Developmental Disability Neuropsychiatry (3DN)	(02) 9931 9160
Co-Investigators	Prof. Karen Fisher	Social Policy Research Centre, UNSW Australia	(02) 9385-7800
Student Researcher	Bronwyn Newman	Social Policy Research Centre, UNSW Australia	(02) 9931 9160
Research Funder	This research is funded by the National Health and Medical Research Council		

### 3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- You are over 18
- have an intellectual disability and
- would like to talk about how you get information about health
- or if you have been included by a person with intellectual disability to support them in this research project.

#### **4. Do I have to take part in this research study?**

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

#### **5. What does participation in this research require, and are there any risks involved?**

If you decide to take part in the research study, you will be asked to participate in a face to face interview at NSW CID or a place convenient to you. You will be asked questions about how people with intellectual disability get information about health. It should take up to an hour to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. The information will be transcribed by the researcher, Bronwyn Newman and stored on a secure UNSW server. If you would like to participate but do not wish to be audio recorded, please let the researcher know and we can discuss other options, such as taking written notes.

We don't expect the questions to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance. If you would prefer to speak to someone not involved in the project please see the numbers listed below.

#### **6. What are the possible benefits to participation?**

We hope to use information we get from this research study to guide services who provide health information to people with intellectual disability.

If you decide to participate in this project you will be provided a \$40 gift voucher to reimburse costs and recognise your time and effort in participating.

#### **7. What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your identifiable information, such as consent forms and audio recording, will be stored securely at the university and destroyed after 7 years.

Researchers at UNSW are required to store their anonymized data in the UNSW data storage system, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your identity will not be identifiable.

Your information will only be used for a research report and to share general findings with service providers and policy makers. The information collected for this research project will be made available to others in a way that participants cannot be identified.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

#### **8. How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you.  
If you would like to receive a copy of the results you can let the research team know by adding your email or postal address to the consent form. We will only use these details to send you the results of the research.

**9. What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or NSW CID.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

The research team will destroy any information about you that was collected during your participation in the study.

**10. What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

<b>Name</b>	Bronwyn Newman
<b>Position</b>	PhD student
<b>Telephone</b>	(02) 9931 9160
<b>Email</b>	<a href="mailto:Bronwyn.newman@student.unsw.edu.au">Bronwyn.newman@student.unsw.edu.au</a>

**Support Services Contact Details**

If at any stage during the study you become distressed or require additional support from someone not involved in the research please call:

<b>Name/Organisation</b>	Mental Health Line
<b>Position</b>	The Mental Health Line is a 24-hour telephone service operating seven days a week across NSW. It provides connections to crisis support and counselling.
<b>Telephone</b>	1800 011 511

**What if I have a complaint or any concerns about the research study?**

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

**Complaints Contact**

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+ 61 2 9385 6222

<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>HC Reference Number</b>	17146

## Consent Form – Participant providing own consent

### Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ I understand that the research team will audio/video record the interviews; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

- ☐ I understand that I will be given a signed copy of this document to keep;

### Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

### Declaration by Researcher\*

- ☐ I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

### Researcher Signature\*

Name of Researcher (please print)	
Signature of Researcher	
Date	

**\*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

**Note: All parties signing the consent section must date their own signature.**

## Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, or NSW

CID. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

**Participant Signature**

Name of Participant (please print)	
Signature of Research Participant	
Date	

**The section for Withdrawal of Participation should be forwarded to:**

CI Name:	Prof. Julian Trollor
Email:	J.Trollor@unsw.edu.au
Phone:	(02) 9931 9160
Postal Address:	Department of Developmental Disability Neuropsychiatry (3DN) 34 Botany Street University of New South Wales Sydney NSW 2052

## Appendix 12: Easy read information and consent form

NOTE: this is an example only. Logos and contact details differed at health sites

 Council for Intellectual Disability	 Ombudsman New South Wales	 Mental Health Review Tribunal	 ACI NSW Agency for Children's Issues	 UNSW AUSTRALIA
 NSW GOVERNMENT	 Mental Health Commission of New South Wales	 Inclusion Australia enabling better, transforming attitudes, connecting people	 NDS National Disability Services	
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Interview				
Project participant Research about Easy Read information Chief Investigator: Julian Trollor				

### Research about Easy Read information

I am a researcher. My job is to ask people about a topic and then use what everyone said to help people. I do this by writing and talking about what everyone said and about what should happen now.

I would like to ask about how you find out information about health. I want to talk to about what Easy Read is and whether you use it.

I'll ask questions about:



- How you like to learn new things
- Whether you like to talk and listen or have things on a piece of paper
- whether you like someone with you at medical appointments



Talking with me will take up to an hour.

You can have help to talk with me and answer the questions. You can ask someone you trust. We can also talk together alone if you want this instead.

I'll ask to record what you say, but if you don't want me to, I can write it down instead.



You can choose which questions to answer. You can say no if you don't want to answer a question.

You only have to talk with me if you want to. You can say no. It's your choice. If you say no then no one will be angry and the support you get won't change.

If you decide you want to talk with me *you can change your mind at any time and say no instead.*



I won't tell anyone it was you who gave me the answers. I will keep your name a secret.

I will tell someone if I think you might hurt yourself or others, but I will speak with you before doing so.



You can use the phone numbers and email addresses on the next page to ask people or complain about what I'm doing.



If you want to take part, I need you to sign your name on the form that says 'I want to take part'.

If you want to leave the research later, you can sign your name on the form that says 'I changed my mind – I don't want to take part anymore' or tell someone who will contact us.

Thank you,

Bronwyn Newman and the other researchers



## People to talk to about the research



If you have questions about the research, you can talk to Bronwyn Newman at the University of New South Wales at [bronwyn.newman@student.unsw.edu.au](mailto:bronwyn.newman@student.unsw.edu.au) or (02) 9931 9160.



If you want to complain about the research, talk with the Ethics Secretariat at the University of New South Wales at [humanethics@unsw.edu.au](mailto:humanethics@unsw.edu.au) or 02 9385 6222. Tell them this number: 17146

If you feel sad or upset after answering the questions, you can call the Mental Health Line on 1800 011 511 and they will talk with you.

## I want to take part in the research



☐ I am signing this form because I want to talk with you about 'Easy Read' information.

.....

My signature

.....

Signature of someone who saw me sign the form

.....

Write your name here

.....

Write their name here

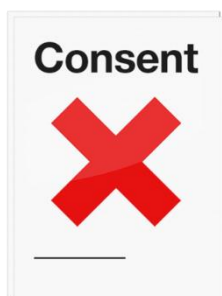
.....

.....

Date

Write how they know you

## I changed my mind – I don't want to take part anymore



I am signing this form because I changed my mind. I don't want to take part in the research about 'Easy Read' anymore and I don't want you to use what I said.

.....

My signature

.....

Signature of someone who saw me  
sign the form

.....

Write your name here

.....

Write their name here

.....

Date

.....

Write how they know you

Please return signed form to Bronwyn Newman at University of New South Wales at [bronwyn.newman@student.unsw.edu.au](mailto:bronwyn.newman@student.unsw.edu.au) or fax (02) 9931 9154 or phone (02) 9931 9160.

## Appendix 13: Easy read information and consent (without pictures)

NOTE: this is an example only. Logos and contact details differed at health sites

	
<b>PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Interview</b>	
Project participant Research about Easy Read information Chief Investigator: Julian Trollor	

### Research about Easy Read information

I am a researcher. My job is to ask people about a topic and then use what everyone said to help people. I do this by writing and talking about what everyone said and about what should happen now.

I would like to ask about how you find out information about health. I want to talk to about what Easy Read is and whether you use it.

I want to ask questions about:

- what makes information easy to understand
- how you like to learn new things
- the people who support you to find out about health information

Talking with me will take up to an hour.

You can have help to talk with me and answer the questions. You can ask someone you trust. We can also talk together alone if you want this instead.

I'll ask to record what you say, but if you don't want me to, I can write it down instead.

You can choose which questions to answer. You can say no if you don't want to answer a question.

You only have to talk with me if you want to. You can say no. It's your choice. If you say no then no one will be angry and the support you get won't change.

If you decide you want to talk with me *you can change your mind at any time and say no instead.*

I won't tell anyone it was you who gave me the answers. I will keep your name a secret.

I will tell someone if I think you might hurt yourself or others, but I will speak with you before doing so.

You can use the phone numbers and email addresses on the next page to ask people or complain about what I'm doing.

If you want to take part, I need you to sign your name on the form that says 'I want to take part'.

If you want to leave the research later, you can sign your name on the form that says 'I changed my mind – I don't want to take part anymore' or tell someone who will contact us.

Thank you,

Bronwyn Newman and the other researcher

## People to talk to about the research

If you have questions about the research, you can talk to Bronwyn Newman at the University of New South Wales at [bronwyn.newman@student.unsw.edu.au](mailto:bronwyn.newman@student.unsw.edu.au) or (02) 9931 9160.

If you want to complain about the research, talk with the Ethics Secretariat at the University of New South Wales at [humanethics@unsw.edu.au](mailto:humanethics@unsw.edu.au) or 02 9385 6222.  
Tell them this number: HC 17146

If you feel sad or upset after answering the questions, you can call the Mental Health Line on 1800 011 511 and they will talk with you.

☐ I am signing this form because I want to talk with you about Easy Read information.

.....

My signature

.....

Signature of someone who saw me  
sign the form

.....

Write your name here

.....

Write their name here

.....

Date

.....

Write how they know you

## I changed my mind – I don't want to take part anymore

I am signing this form because I changed my mind. I don't want to take part in the research Easy Read anymore and I don't want you to use what I said.

.....

My signature

.....

Signature of someone who saw me  
sign the form

.....

Write your name here

.....

Write their name here

.....

Date

.....

Write how they know you

Please return signed form to Bronwyn Newman at University of New South  
Wales at [bronwyn.newman@student.unsw.edu.au](mailto:bronwyn.newman@student.unsw.edu.au) or fax (02) 9931 9154 or  
phone (02) 9931 9160.

## Appendix 14: Participant information and consent (parent/guardian of an adult)

NOTE: this is an example only. Logos and contact details differed at health sites

	
<b>PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Parent Guardian</b>	
Research about Easy Read information. Chief Investigator: Julian Trollor	

### 1. What is the research study about?

This is an invitation for you and your child in your care to take part in this research project, which is called Easy Read information for people with intellectual disability. You have been invited because your child uses services at [SERVICE NAME].

### 2. Who is conducting this research?

The study is being carried out by the following researchers: **Julian Trollor, Karen Fisher and Bronwyn Newman at the University of NSW**, this research is being funded by the National Health and Medical Research Council.

### 3. Inclusion/Exclusion Criteria

Before you decide to allow your child to participate in this research project, we need to ensure that it is ok for your child to take part. The research study is looking for children that meet the following criteria:

- Has an intellectual disability
- Over 16 years
- Would like to tell the researcher about how they access health information

### 4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you or your child does not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

### 5. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, you will be asked to participate in a face to face interview at [SERVICE NAME] or a place convenient to you. You will be asked questions about how people with intellectual disability get information about health. It should take up to an hour to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. The information will be transcribed by the researcher, Bronwyn Newman and stored on a secure UNSW server. If you would like to participate but do not wish to be audio recorded, please let the researcher know and we can discuss other options, such as taking written notes.

We don't expect the questions to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance. If you would prefer to speak to someone not involved in the project please see the numbers listed below.

**6. What are the possible benefits to participation?**

We hope to use information we get from this research study to guide services who provide health information to people with intellectual disability.

**7. What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using information about your child for the research study. Your identifiable information, such as consent forms and audio recording, will be stored securely at the university and destroyed after 7 years.

Your child's information will only be used for a research report and to share general findings with service providers and policy makers. The information collected for this research project will be made available to others in a way that participants cannot be identified.

Researchers at UNSW are required to store their any aggregated data in the UNSW data repository, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your child's identity will not be known.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

**8. How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you or your child.

If you would like to receive a copy of the results you can let the research team know by adding your email or postal address within the consent form. We will only use these details to send you the results of the research.

**9. What if I want to withdraw from the research study?**

If you and your child do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively, you can ring the research team and tell them you no longer want your child to participate. Your decision not to participate or to withdraw your child from the study will not affect your relationship with UNSW Sydney or [SERVICE NAME].

If you decide to leave the research study, the researchers will not collect additional information from you or your child. Any identifiable information about you or your child will be withdrawn from the research project.

**10. What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the following member/s of the research team:

**Research Team Contact Details**



<b>Name</b>	Bronwyn Newman
<b>Position</b>	PhD student
<b>Telephone</b>	(02) 9931 9160
<b>Email</b>	<a href="mailto:Bronwyn.newman@student.unsw.edu.au">Bronwyn.newman@student.unsw.edu.au</a>

### Support Services Contact Details

If at any stage during the study you become distressed or require additional support from someone not involved in the research please call:

<b>Name/Organisation</b>	Mental Health Line
<b>Position</b>	The Mental Health Line is a 24-hour telephone service operating seven days a week across NSW. It provides connections to crisis support and counselling.
<b>Telephone</b>	1800 011 511

### What if I have a complaint or any concerns about the research study?

This study has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email SESLHD-RSO@health.nsw.gov.au and quote [HREC project number].

[Add for Multi-site research] The conduct of this study at the [name of site] has been authorised by the [name of health district]. Any person with concerns or complaints about the conduct of this study may also contact the [details of the Research Governance Officer of the health district]

## Consent Form – Parent/Guardian Consent

### Declaration by the participant

- ☐ I understand I am being asked to provide consent to allow my child to participate in this research project;
- ☐ I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- ☐ I understand the aim of this research and have been given a description of the study tasks and I understand what my child will be asked to do;
- ☐ I understand that the research team will audio record my child during the interviews and/or focus groups the interviews; I provide my consent for this to happen.
- ☐ I provide my consent for the information collected about me or my child to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I understand that I will be given a signed copy of this document to keep;
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email Address: \_\_\_\_\_

**Parent/Guardian Signature**

Name of Participant (please print)	
Signature of Research Participant	
Date	

**Declaration by Researcher\***

- ☐ I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

**Researcher Signature\***

Name of Researcher (please print)	
Signature of Researcher	
Date	

\*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.

**Note:** All parties signing the consent section must date their own signature.

## Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent for my child to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, or [SERVICE NAME]. In withdrawing my consent I would like any information collected from me or my child that has been provided for the purpose of this research project withdrawn.

**Participant Signature**

Name of Participant (please print)	
Signature of Research Participant	
Date	

**The section for Withdrawal of Participation should be forwarded to:**

CI Name:	Prof. Julian Trollor
Email:	J.Trollor@unsw.edu.au
Phone:	(02) 9931 9160

Postal Address:	Department of Developmental Disability Neuropsychiatry (3DN) 34 Botany Street University of New South Wales Sydney NSW 2052
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## Appendix 15: Participant information and consent (carer/supporter of a child under 16)

NOTE: this is an example only. Logos and contact details differed at health sites

<p align="center"><b>PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Interview</b></p> <p align="center">Project participant Research about Easy Read information Chief Investigator: Julian Trollor</p>	

### 1. What is the research study about?

You are invited to take part in this research study. The research study aims to explore how Easy Read is used to make information more accessible. We are especially interested in how people with intellectual disability access information about health.

### 2. Who is conducting this research?

**This study is part of a PhD about Easy Read conducted by Ms Bronwyn Newman.**

The study is being carried out by the following researchers:			
Role	Name	Organisation	Telephone
<b>Chief Investigator</b>	Prof. Julian Trollor	Department of Developmental Disability Neuropsychiatry (3DN)	(02) 9931 9160
<b>Co-Investigators</b>	Prof. Karen Fisher	Social Policy Research Centre, UNSW Australia	(02) 9385-7800
<b>Student Researcher</b>	Bronwyn Newman	Social Policy Research Centre, UNSW Australia	(02) 9931 9160
<b>Research Funder</b>	This research is funded by the National Health and Medical Research Council		

### 3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet one of the following criteria:

- you are the parent or guardian of a child under 16 who accesses services at [SERVICE NAME]
- you support someone with intellectual disability who uses [SERVICE NAME] and you have their permission to be interviewed in this project.

### 4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

#### **5. What does participation in this research require, and are there any risks involved?**

If you decide to take part in the research study, you will be asked to participate in a face to face interview at [SERVICE NAME] or a place convenient to you. You will be asked questions about how people with intellectual disability get information about health. It should take up to an hour to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. The information will be transcribed by the researcher, Bronwyn Newman and stored on a secure UNSW server. If you would like to participate but do not wish to be audio recorded, please let the researcher know and we can discuss other options, such as taking written notes.

We don't expect the questions to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance. If you would prefer to speak to someone not involved in the project please see the numbers listed below.

#### **6. What are the possible benefits to participation?**

We hope to use information we get from this research study to guide services who provide health information to people with intellectual disability.

#### **7. What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your identifiable information, such as consent forms and audio recording, will be stored securely at the university and destroyed after 7 years.

Researchers at UNSW are required to store their anonymized data in the UNSW data storage system, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your identity will not be identifiable.

Your information will only be used for a research report and to share general findings with service providers and policy makers. The information collected for this research project will be made available to others in a way that participants cannot be identified.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

#### **8. How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by adding your email or postal address to the consent form. We will only use these details to send you the results of the research.

**9. What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or [SERVICE NAME]

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

The research team will destroy any information about you that was collected during your participation in the study.

**10. What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

<b>Name</b>	Bronwyn Newman
<b>Position</b>	PhD student
<b>Telephone</b>	(02) 9931 9160
<b>Email</b>	<a href="mailto:Bronwyn.newman@student.unsw.edu.au">Bronwyn.newman@student.unsw.edu.au</a>

**Support Services Contact Details**

If at any stage during the study you become distressed or require additional support from someone not involved in the research please call:

<b>Name/Organisation</b>	Mental Health Line
<b>Position</b>	The Mental Health Line is a 24-hour telephone service operating seven days a week across NSW. It provides connections to crisis support and counselling.
<b>Telephone</b>	1800 011 511

**What if I have a complaint or any concerns about the research study?**

This study has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email SESLHD-RSO@health.nsw.gov.au and quote [HREC project number].

[Add for Multi-site research] The conduct of this study at the [name of site] has been authorised by the [name of health district]. Any person with concerns or complaints about the conduct of this study may also contact the [details of the Research Governance Officer of the health district]

## Consent Form – Participant providing own consent

### Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ I understand that the research team will audio/video record the interviews; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

- ☐ I understand that I will be given a signed copy of this document to keep;

### Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

### Declaration by Researcher\*

- ☐ I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

### Researcher Signature\*

Name of Researcher (please print)	
Signature of Researcher	
Date	

**\*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

**Note: All parties signing the consent section must date their own signature.**

## Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, or [SERVICE NAME]. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

### Participant Signature

Name of Participant  (please print)	
Signature of Research Participant	
Date	

### The section for Withdrawal of Participation should be forwarded to:

CI Name:	Prof. Julian Trollor
Email:	J.Trollor@unsw.edu.au
Phone:	(02) 9931 9160
Postal Address:	Department of Developmental Disability Neuropsychiatry (3DN)  34 Botany Street  University of New South Wales  Sydney NSW 2052





## Appendix 17: Project advertising (carer/supporter)



### Easy read Information for people with intellectual disability



Researchers at UNSW Sydney (The University of New South Wales) want to learn about how people with intellectual disabilities use Easy Read to get information about health.

#### Would the research study be a good fit for me?

The study might be a good fit for you if:

- You support someone who has an intellectual disability to use services at [SERVICE NAME]

#### What would happen if I took part in the research study?

If you decide to take part:

- The researcher would ask you some questions about finding out health information
- This would take up to an hour and you can bring someone with you to support you if you would like to.

#### Will I be paid to take part in the research study?

You will be provided a gift voucher to reimburse costs and recognise your time and effort in participating.

#### Who do I contact if I want more information or want to take part in the study?

This research is part of Bronwyn Newman's PhD. If you would like more information or are interested in being part of the study please contact:

Name: Bronwyn Newman  
[Bronwyn.newman@student.unsw.edu.au](mailto:Bronwyn.newman@student.unsw.edu.au)  
Phone: (02) 9931 9180

HREC Approval Number: 17/111  
Participant group: Carers and Supporters

Version dated: 20 June 2017

## Appendix 18: Verbal consent script

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### 1. Introduction

I am Bronwyn Newman from the University of NSW. I am conducting a research study about how Easy Read is used by people with intellectual disability and their carers /advocates. I am especially interested in how people get information about health.

### 2. Invitation

I would like to invite you to participate in this research study. Before we go any further I need to let you know that participation in this research study is voluntary. If you do not want to take part, you do not have to. Are you happy for me to provide you with further information on the research study?

- ☐ If no, thank the participant for their time and end the consent process.
- ☐ If yes, proceed with the following information.

### 3. Description of participation

If you decide to take part in the research study, we will ask you to answer some questions. It should take up to an hour to complete. We don't expect the interview to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance.

### 4. Data storage and use

During the research study we will collect information from you relevant to this research study. Your data will be kept for 7 years after the project's completion. Your information will only be used for a research report and general information about what we learn might be shared in reports for health organisations to see, but no organisations or individuals will be identified in the information that is shared. Any information we collect from you will be stored and presented in research publications in a way that will not identify you.

### 5. Withdrawal from the research

If you decide to leave the research study, we will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Australia or [SERVICE].

### 6. Questions

Do you have any questions in regard to the information that I have provided?

- ☐ If yes, answer any questions the participant may have
- ☐ If no, continue to collect consent.

If you would like, I will send you an email/letter containing the details of the person for you to contact if you have any questions or complaints about the research study.

### 7. Consent

Now that I have explained what your involvement in the research study requires, are you happy to provide your consent to participate in the study?

- ☐ If no, thank the participant for their time and end the consent process.
- ☐ If yes, ensure you record the time and date the verbal consent was collected from the participant. Furthermore, you will need to ask the participant if:
  - they would like a copy of the participant information sheet sent to them;
  - They are happy to be audio recorded.

→ Commence with data collection

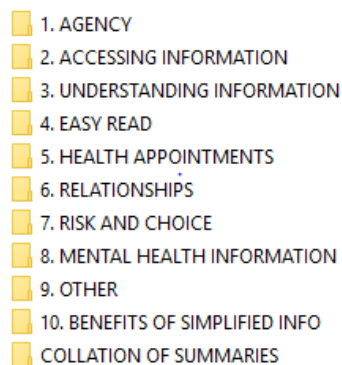
## Appendix 19: Data analysis

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A folder was created for each agency:



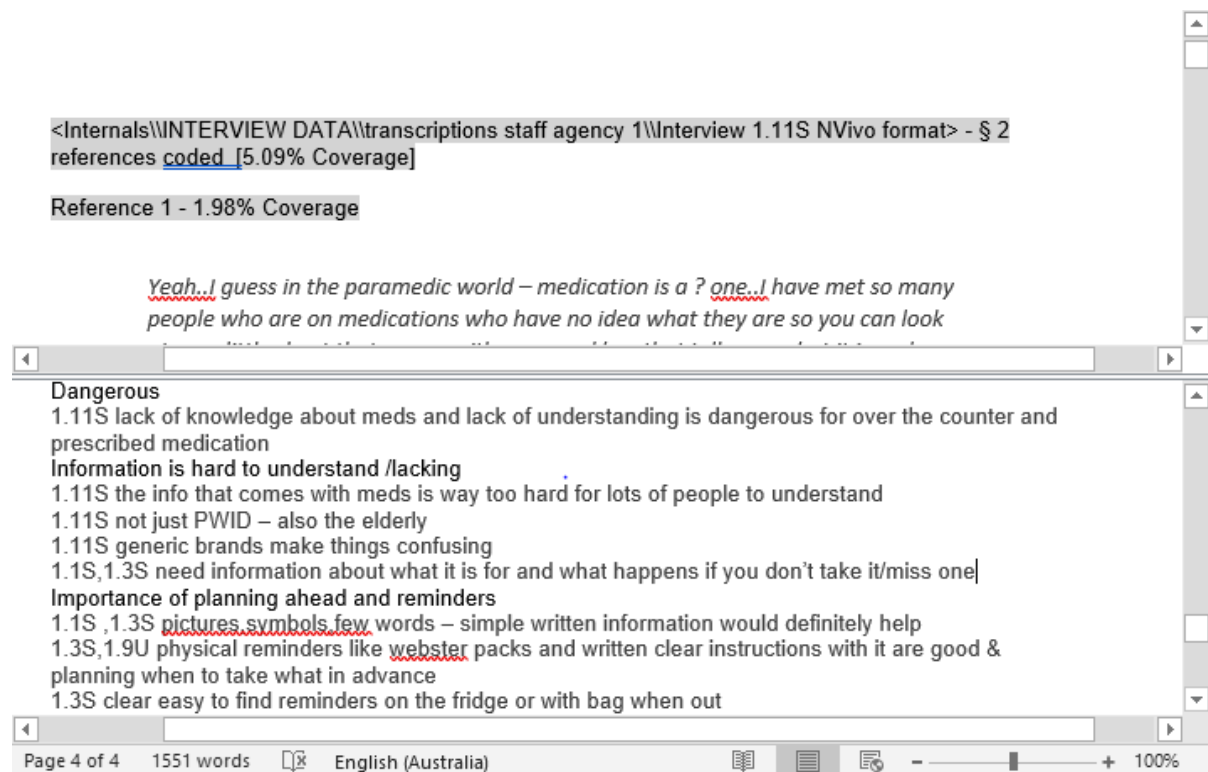
Within each folder sub folders were created which represented the coding tree. The raw data from each NVivo node which contained sub-themes according to the Agency was stored in the folder as follows:



*aptured image from computer drive)*

Figure 5 displays the NVivo data with identifier and a chunk of transcript at the top with the emerging list of summary information below. The summary information groups like themes and lists the participants who raised the issue mentioned. In this instance the folder being analysed is from Agency 1 about medication. The summary on the bottom half of the screen was used to develop a list of data about the topic area.

Figure 4 Captured image of split screen



(captured image from computer drive)

## Appendix 20: Summary of policy analysis findings

Policy	ID mentioned	UNCRPD mentioned	Accessible information	Involvement in Planning	Carer Support
<b>COMMONWEALTH-MENTAL HEALTH</b>					
eMental Health Plan 2012	-	-	x	x	-
Fifth National Mental Health Plan 2017	x	x	x	x	x
Mental health statement of rights and responsibilities 2012	x	x	x	x	x
National Aboriginal & Torres Strait Islander Suicide Prevention Strategy 2013	-	-	x	x	x
National Mental Health Policy 2008	-	-	x	x	x
Report of the National Review of Mental Health Programs and Services 2014	x	?	x	x	x
Roadmap for National Mental Health Reform (COAG) 2012-2022	x	-	x	x	x
The Living Is For Everyone (LIFE) Framework 2007	-	-	x	x	x
<b>COMMONWEALTH – HEALTH</b>					
Male Health Plan: Building on the Strengths of Australian Males 2009-12	-	-	x	-	-
National Aboriginal and Torres Strait Islander Health Plan 2013-2023	x	-	x	x	-

National Drug Strategy 2010-2015	-	-	X	-	X
National Women's Health Policy 2010	-	-	X	X	-
<b>COMMONWEALTH-DISABILITY</b>					
COAG National Disability Agreement 2009	-	X	X	X	X
Disability Discrimination Act 1992	X		X	X	X
Disability Services Act 1986	X	X	X	X	X
National Disability Insurance Scheme Act 2016	X	X	X	X	X
National Disability Service Standards 2013	-	X	X	X	X
National Disability Strategy 2010-2020	X	X	X	X	X
<b>NSW MENTAL HEALTH</b>					
NSW Health Aboriginal Mental Health and Well Being Policy 2006-2010	-	-	X	X	X
NSW Health Living Well Mental Health Policy 2014-2024	X	X	X	X	X
NSW Older People's Mental Health Services SERVICE PLAN 2017-2027	X	-	X	X	X
NSW School-link Strategic Action Plan 2014-2017	-	-	X	X	X
Safe start Policy and Guidelines 2010	X	-	X	X	X
<b>NSW HEALTH</b>					
Male Health plan 2009-12	-	-	X	X	-
Mental Health Act No.8 2007 (amended 2015)	X	-	X	X	X
Mental Health Commission Act 2012	-	-	-	-	X
Memorandum of Understanding (MOU) between ADHC and NSW Health 2010	X	-	-	X	X

NSW Health Aboriginal Health Plan 2013-2023	-	-	-	X	X
NSW Health Plan towards 2021, 2014	-	-	X	X	-
NSW Health Disability Action Plan	X	X	X	X	X
Women's health plan 2009-2011	X	-	X	X	X
Youth Health Policy 2017-2024	X	-	X	X	X
<b>NSW HEALTH DIRECTIVES AND GUIDELINES</b>					
Aggression, Seclusion & Restraint in Mental Health Facilities - Guideline Focused Upon Older People 2012	X	-	X	X	X
Aggression, Seclusion & Restraint in Mental Health Facilities in NSW 2012	-	-	-	X	X
Call Handling Guidelines for Mental Health Telephone Triage Services 2012	-	-	X	X	-
Chief Psychiatrist Panel Review of Complex Mental Health Treatment Plans (policy) 2011	-	-	-	-	X
Children and Adolescents - Safety and Security in NSW Acute Health Facilities (policy) 2010	-	-	-	-	X
Children and Adolescents with Mental Health Problems Requiring Inpatient Care (policy) 2011	X	-	-	X	X
Clinical care of people who may be suicidal (policy) 2016	-	-	-	X	X
Engagement and Observation in Mental Health Inpatient Units (policy) 2017	-	-	-	X	X
Forensic Mental Health Services (policy) 2012	X	-	X	X	-
Management of patients with Acute Severe Behavioural Disturbance in Emergency Departments 2015	X	-	X	X	X
Mental Health Triage Policy 2012		-	X	X	X
	X				



NSW Specialist Mental Health Services for Older People (SMHSOP) Acute Inpatient Unit Model of Care Guideline 2016	x	-	x	x	x
Principles for Safe Management of Disturbed and/or Aggressive Behaviour and the Use of Restraint (not in mental health facilities) 2015	x	-	x	-	x
Psychiatric Emergency Care Centre Model of Care Guideline 2016	x	-	?	x	x
Sexual Safety - Responsibilities and Minimum Requirements for Mental Health Services 2013	-	-	x	x	x
Sexual Safety of Mental Health Consumers Guidelines 2013	x	-	x	x	x
Transfer of Care from Mental Health Inpatient Services 2016	x	-	-	-	x

#### AGENCY 1 DOCUMENT DESCRIPTIONS

Discharge and peer support	-	-	x	x	x
Community visits	-	-	-	-	-
Communication	-	-	x	-	-
Committee representation	-	-	x	-	-

#### AGENCY 2 DOCUMENT DESCRIPTIONS

Clinical Risk Assessment and management	x	-	x	x	x
Emergency sedation	-	-	-	-	x
	-	-	x	-	-
Patient Care Levels					
Patient Leave from Acute care	-	-	x	x	x
Identify and Respond to domestic violence	x	x	-	x	x

Extended Seclusion and governance	-	-	-	-	-
Committee representation	-	-	-	-	--
Telephone support	-	-	-	-	-
<b>AGENCY 3 DOCUMENT DESCRIPTIONS</b>					
Admission procedures	-	-	X	-	X
Factsheet development	-	-	X	-	X
Care guidelines for people with cooccurring intellectual disability and mental ill-health	X	-	X	X	X
Psychiatric patient transfer	-	-	-	-	-
Rights and responsibilities	-	-	X	X	X

## Appendix 21: Easy read at Agency 4

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Agency 4 participants defined easy read documents as simplified text, most often with corresponding pictures. Easy read creators at Agency 4 did not agree on all technical aspects of easy read design, however they all said that easy read made information more understandable. For example, some staff had specific ideas about font size, full stop use and picture placement that they did not always agree on. As discussed in the background (Chapter 1) there was limited agreement in the literature and easy read guides about what constitutes easy read and the findings at Agency 4 were reflective of this. Agency 4 participants said that collaboration with people with intellectual disability when developing information was an important element to make it understandable. Listed below are the key easy read features articulated by Agency 4 participants.

### **Features of Easy Read:**

- have key messages in mind – one key message per page
- simple text is better – but not necessarily less
- use short sentences, simple language and short paragraphs if you have them
- always use large font
- pictures are important but some said not essential in all documents
- usually image on left, text on right
- pictures as reminders, photos of actual things are good, some people like colours
- it is important that appropriate pictures are chosen for the culture of the user
- lots of spacing, no borders
- not too many pages
- the rules often change e.g. some like full stops and others do not
- include a practical what to do next or where to find out more

Participants at Agency 4 were enthusiastic about increasing the availability of easy read and shared many uses which have potential application for easy read about mental health. The examples described by Agency 4 staff included forms, legal documents and brochures which contained difficult concepts. Some easy read documents created by Agency 4 were for individual circumstances and others for generic use. Agency 4 staff described that they sometimes developed easy read documents from start to finish and at other times they adapted pre-existing material. Below are some examples of easy read documents created by Agency 4.

**Some examples of easy read documents produced:**

Easy read information created by Agency 4 is used in various settings. Examples include:

- Community information flyers e.g. event information or health guides
- Complex documents such as contracts or policy e.g. accommodation agreement
- Documents for individual users e.g. Travel itinerary, a letter, meeting agenda.