

Module 1 – Introduction to Intellectual Disability

Topic 1. What is Intellectual Disability?

1. MEDICAL AND DIAGNOSTIC DEFINITIONS

a) Definition

There is no single, agreed definition of ‘intellectual disability’. In Australia and internationally, the most commonly used definitions are those outlined by the American Association on Intellectual and Developmental Disabilities (2010), the World Health Organization (2010), and the American Psychiatric Association – DSM-V (2013). The American Association on Intellectual and Developmental Disabilities (2010) defines Intellectual Disability as follows:

“Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (AAIDD, 2010).

b) Diagnostic Criteria

Intellectual disability is formally diagnosed by a qualified professional using diagnostic criteria and testing tools. Across different diagnostic systems, three key criteria are used to establish a diagnosis of intellectual disability:

- i.* Significant limitations in intellectual functioning (measured using IQ testing); and
- ii.* Significant limitations in adaptive behaviour (measured using adaptive behaviour scales); and
- iii.* Originates before age 18 (Hodapp & Dykens, 2004; Australian Institute of Health & Welfare, 2008).

c) Prevalence

Two to three per cent of Australians meet the criteria for a diagnosis of intellectual disability (AIHW, 2008). This increases to thirteen percent when expanded to include ‘borderline’ intellectual disability (IQ 70-84) (AIHW, 2008; Ferrari, 2009). It is important to note that some people with intellectual disability may not have received a formal diagnosis, or may choose to

describe their experience of intellectual disability in their own way. Some people with intellectual disability may not acknowledge their experience of disability.

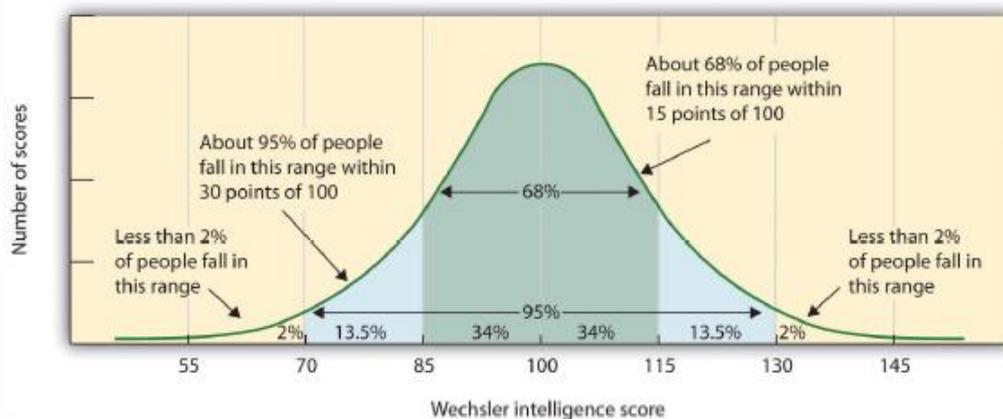
2. INTELLECTUAL FUNCTIONING

Intellectual functioning (also called intelligence) refers to general mental capacity, such as learning, reasoning, abstract thinking, comprehending ideas and concepts, problem solving, memory, planning, and so on. People with intellectual disability will find it difficult to do some or all of these things; may do them more slowly; or may not be able to do them at all (Bigby & Frawley, 2010, p. 8).

IQ testing

One way to measure intellectual functioning is an IQ test. There are various IQ assessment tools that are used for different purposes and age groups. Some common tools are the Wechsler Intelligence Scales and the Stanford Binet Intelligence Scales. The diagram below (Stangor, 2010) shows the distribution of IQ scores in the general population, using the Weschsler Intelligence Scale.

- 68% of IQ test takers will record an IQ score between 85-114 (commonly termed 'Average' intellectual functioning)
- 13.5% of IQ test takers will record an IQ score 70-84 ('Borderline' intellectual functioning)
- 2% of IQ test takers will record an IQ score 69 or lower (Significant limitation in intellectual functioning or intellectual disability).



3. ADAPTIVE BEHAVIOUR

Adaptive behaviour is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives. Three domains of adaptive functioning are:

- **Conceptual skills** relate to cognition, communication and academic tasks, such as use of language and literacy; communication; money, time, and number concepts; reasoning, knowledge and memory.
- **Social skills** relate to the conduct of interpersonal relationships, empathy, social judgement, self-esteem, responsibility, gullibility, social problem solving, and the ability to follow rules/obey laws, ability to make and retain friendships.
- **Practical skills** are connected to activities of daily living, such as eating, mobility, toileting, dressing (personal care), and instrumental activities of everyday living such as cooking, shopping, household management, money management, travel/transportation; use of telephone and computers; occupational skills; and organisational skills (e.g. schedules/routines for organising school and work tasks).

While standardized tests are used to formally determine limitations in adaptive behaviour, behaviour and functioning can also be observed by spending time with a person. People with limitations in adaptive behaviour will have difficulty with many of these skills and will require support to manage their everyday lives (Bigby & Frawley 2010, p.8-9).

4. DEGREES OF IMPAIRMENT

You may be familiar with labels commonly applied to different degrees of intellectual disability, classified using IQ scores (for example, *Mild, Moderate, Severe & Profound*). These categorisations can provide some indication of what we might expect people's abilities and support needs to be. At the same time, we must remember that needs depend on individual factors:

“Arbitrary categories of mild, moderate, severe and profound levels of intellectual disability are defined on the basis of IQ scores. These levels give some guide to the level of support someone might need but the way a person functions in their life also depends on other factors including: personality, coping skills, other disabilities – for example, physical, social or sensory, the amount of support offered by family, friends and the community, what is demanded of them in different situations” (CDDHV, 2015).

- **13.6% of IQ test takers will score between 70 and 84 (categorized as ‘Borderline’ Intellectual Disability).** This level of intellectual functioning is considered part of the ‘normal variation’ in intelligence, however, people with ‘borderline’ intellectual disability often struggle to meet contemporary society’s increased demand for high level intellectual functioning, and are at considerable risk for academic difficulties, vocational challenges, poor adaptation, and the development of mental illness. (Ferrari, 2009; Fernell & Ek, 2010). Prior to 1973, borderline intellectual disability was within the distribution of IQ scores signaling intellectual disability. In 1973, in response to criticism of high prevalence rates of intellectual disability, the AAIDD revised the IQ scores indicating intellectual disability from 1 to 2 standard deviations from the mean (IQ100). Overnight, 13.6% of people were ‘declassified’ from having an intellectual disability.
- **80-90 percent of people with intellectual disability score in the IQ 50-69 range (categorised as ‘Mild’ Intellectual Disability).** This level of impairment is often described as ‘Mild’ Intellectual Disability, however, this terminology minimises the seriousness and challenges of living with this type of intellectual impairment. Typical difficulties for people with ‘mild’ intellectual disability will include problems with the subtleties of interpersonal relationships and social rules, difficulties with reading and writing and academic learning; difficulties handling money,; and difficulties with problem solving, planning and organisation in daily life.

“Generally speaking, a person with mild intellectual disability participates in and contributes to their families and their communities, has important relationships in his/her life, works in either open or supported employment, may live and travel independently but will need support and help to handle money and to plan and organise their daily life, may marry and raise children with the support of family, friends and the service system, may learn to read and write” (CDDH Victoria, 2015).

- **Approximately 10 per cent of people with intellectual disability score in the IQ 35-49 range (categorised as Moderate Intellectual Disability).** People with a moderate intellectual disability will have noticeable developmental delays impacting on speech and motor skills; they will typically have difficulties with planning, managing money, problem solving, & social skills; and will require support to learn and manage tasks of everyday life.

“Generally speaking, a person with a moderate intellectual disability has important relationships in his/her life, enjoys a range of activities with their families, friends and acquaintances, understands daily schedules or future events if provided with pictorial

visual prompts such as daily timetables and pictures, makes choices about what s/he would like to do, eat, drink, etc, may learn to recognise some words in context, such as common signs including 'Ladies', 'Gents', and 'Exit', may develop independence in personal care, will need lifelong support in the planning and organisation of their lives and activities" (CDDH Victoria, 2015).

- **Approximately 3-4% of people with intellectual disability have a Severe intellectual disability, indicated by an IQ score between 20; and 34. 1-2 % of people with intellectual disability have a Profound intellectual disability, indicated by an IQ score below 20.** People with severe and profound id will require lifelong support with personal care, communication, & accessing and participating in community facilities, services and activities.

"Generally speaking, a person with a severe or profound intellectual disability recognises familiar people and may have strong relationships with key people in their lives, has little or no speech and relies on gestures, facial expression and body language to communicate, requires lifelong help with personal care tasks, communication and accessing and participating in community facilities, services and activities" (CDDH, 2015).

5. SELF-DEFINITIONS

Some people with intellectual disability may not have received a formal diagnosis, while others may not like, identify with, or use the label 'intellectual disability' to describe themselves. It is very important that service providers and support workers take the time to explore how a person with intellectual disability describes their experience of intellectual impairment. Many people prefer the terms 'learning disability' or 'learning difficulty' to describe their intellectual disability. Some people may use other disability labels to explain their experiences - for example, autism, depression, or cerebral palsy. Some people describe their intellectual disability in their own personal way.

"I'm someone who takes a while to learn things".

"I have a learning difficulty and am no different from you. I can be hurt and I can be happy".

"I've got a disability and it takes me longer to work things out. But just because it takes me longer doesn't mean I can't do it! "

"I'm is no good at remembering – I forget things quickly"

"I'm no good at doing things e.g. knowing left from right"

"This is because I hardly ever went to school. I was picked on and had my books ripped up and the teachers wouldn't do anything about it".

“I’m not listened to. People talk to me like I’m a child”.

“People make me feel like I’m stupid, no good, worthless”.

Self-definitions are valuable because they enable people without an intellectual disability to gain an appreciation of the experience of living with an intellectual disability. Personal descriptions often highlight the practical realities of living with intellectual disability – including difficult tasks (e.g. reading and remembering); and difficult social experiences (e.g. discrimination and bullying).

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Topic 2. Lived Experience of Intellectual Disability: Stigma

People with intellectual disability are a stigmatised group who face many barriers to full participation in community life (Werner, Corrigan, Ditchman & Sokol, 2012). Stigma is the outcome of negative attitudes or stereotypes about a group that lead to prejudice and discrimination toward that group (Werner et al., 2012). *Stigma* is made up of cognitive, emotional, and behavioural dimensions, which in practice are stereotypes (beliefs), prejudice (feelings), and discrimination (actions).

1. RIGHTS AND DISCRIMINATION

Throughout history, people with intellectual disability have been treated in degrading, paternalistic, hostile, disrespectful and sometimes cruel ways. They have been institutionalised, marginalised and systematically pathologised.

Societal views about people with intellectual disability have included a broad spectrum of beliefs ranging from the Eugenics Movement of the early twentieth century which supported the institutionalisation, sterilisation and euthanasia of people with intellectual disability (Goggin & Newell, 2005); to current times where the rights of people with disability to live good lives as valued members of their community are recognised (if not fully realised) through national legislation such as the Commonwealth Disability Discrimination Act (1992) and international charters such as the United Nations Convention on the Rights of Persons with Disabilities (signed and ratified by the Australian government).

People with intellectual disability continue to face major challenges in realising some of their most fundamental human rights. Their rights to self-determine a wide range of fundamental day-to-day life choices are restricted for many people with intellectual disability, including place of residence, choice of co-residency, access to the legal justice system, choice of service providers, choice to enter intimate relationships, choice to parent.

2. MYTHS AND STEREOTYPES

People with disabilities often face social, legal, and practical barriers in claiming their human rights on an equal basis with others. These barriers stem from negative attitudes about disability. Myths and stereotypes about people with disabilities are socially held views that create barriers to social inclusion, limit access to equal opportunity and justice, and are used to justify abuse and neglect of people with disabilities. The University of Minnesota Human Rights Resource Centre

(Lord, J.F., Guernsey, K.N., Balfe, J.M, Karr, V.L. & Flowers, N., 2007) identifies the following common myths or stereotypes about people with disabilities,

- Cannot be self-sufficient/are excessively dependent
- Are to be pitied
- Are helpless
- Are cursed/disability is a punishment for evil
- Are bitter because of their fate
- Resent the non-disabled world
- Have lives not worth living
- Are better off at home
- Cannot work
- Cannot have a family/cannot be good parents
- Are asexual
- Need to be cured and helped by medical professionals
- Need special, separate educational programs
- Cannot be involved in cultural/recreational activities
- Are unable to learn
- (People with intellectual disabilities) are naive, like children, and cannot make any decisions for themselves
- (People with psycho-social disabilities) are dangerous/a threat/violent
- Must use alternative ways of communicating because they are stupid.

Myths and stereotypes about people with intellectual disability underpin discriminatory practices and contribute to people's vulnerability. They limit their ability to access help, deny their rights and obstruct their access to justice. These attitudes are often evident in the cases of sexual violence against people with intellectual disability. They are employed by perpetrators of sexual violence to justify their own inappropriate actions and to prevent the victim from breaking the abusive relationship; and restrict survivor's access to justice in the legal system.

Attitudes that Devalue, Depersonalise and Trivialize their Experience

- People with intellectual disability represent a homogenous group, all with the same needs and abilities.
- Because they are unable to fully comprehend what has happened, they suffer less emotional trauma and psychological injury.

Attitudes that Disempower

- People with an intellectual disability are like children, or are asexual.
- The adversarial nature of the court will overwhelm a person with an intellectual disability; therefore it is not in their best interests to take legal action.

Attitudes that Contribute to their Vulnerability

- People with an intellectual disability are identifiable by physical characteristics.
- They primarily live in institutions where they are protected.
- No one would take advantage of a person with an intellectual disability.
- They are sexually promiscuous and seek out sexual contact.

Attitudes that Deny or Dismiss their Experience

- People with an intellectual disability are prone to fantasize.
- They are unable to distinguish fantasy from fact.
- People with an intellectual disability behave in a manner that invites or provokes victimization.

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Topic 3. Lived Experience of Intellectual Disability: Social Disadvantage

People with intellectual disability are more likely to experience social disadvantage, including multiple types of disadvantage. These experiences include structural disadvantage and discrimination, and result in high rates of social isolation and exclusion from full participation in community life.

People with intellectual disability are more likely to experience social isolation and social exclusion. They may be highly visible in the community and seen to access services and community resources, while opportunities for meaningful engagement and the full range of human relationships outside the disability service system are limited (Craig & Bigby, 2010).

Extensive research demonstrates multiple experiences of social disadvantage by people with intellectual disability. They are:

- Over-represented amongst homeless populations (Oakes & Davis, 2008).
- More likely to experience unemployment. For example, 2012 data from the Australian Bureau of Statistics shows:
 - Around 39% of people with intellectual disability were in the labour force compared with 55% of people with other types of disability and 83% of the non-disabled population.
 - The majority of people with intellectual disability were not in the labour force (61%) compared with just under half of people with other disability types (50%) and 18% of people without disability.
 - Of those in the labour force, people with an intellectual disability were less likely to be employed full-time (12%) than people with other types of disabilities (32%), and people without disability (55%).
 - The unemployment rate for people with intellectual disability was significantly higher (20%) than the unemployment rates for people with other types of disability (8%) and people with no disability (5%)
 - More likely to withdraw from employment earlier in life (AIHW, 2008).
- Often have poor education experiences. Approximately 60% of people with intellectual disability have severe communication limitations and it is common for young people to leave school without basic levels of literacy and numeracy (AIHW, 2008). Many children and young people are placed in special education classes by their fifth year at school; those who are not often receive little extra schooling support (AIHW, 2008). People with intellectual disability are much less likely to undertake tertiary education. *School exclusion*

- Are at much greater risk of experiencing poverty than other members of the population, due to low levels of skills development and reduced capacity, impacting on participation in employment and social opportunities that could contribute to financial security.
- At increased risk of criminal victimisation. For example, 1.5 times more likely to become victims of crime (Wilson et al., 1996); 2.9 times more likely to be physically assaulted; 12.7 times to be the victim of robbery (Petersilla, 2000). Children with intellectual disabilities are 3.4 times more likely to be abused than children without disabilities (reference).
- At increased risk of sexual assault and exploitation. Research suggests between 50-99% of people with intellectual and psychosocial impairments are subject to sexual abuse in their lifetime (French, 2007); Women remain the overwhelming victims of sexual assault - 68% of women with intellectual disability will be sexually abused before they are 18 (Frohman 2002) and over 90% of women will be the victims of violent sexual encounters in their lifetime (Frohman, 2012). However, men with intellectual disability are at increased risk of sexual assault than men in the general population (Murray & Powell, 2008).
- At increased risk of domestic violence and abuse. Women with disabilities are 40% more likely to be the victims of domestic violence than women without disabilities (Brownridge, 2006).
- Experience high rate of undiagnosed illness and health care utilisation. High rates of hospitalisation for infections, respiratory problems, dental conditions and skin disorders. High rates of obesity, nutritional problems, vision and hearing impairment, endocrine disorders and hypertension. Epilepsy prevalence rates of 22% (compared to 0.4% - 1% for the general population). Primary health care access maybe insufficient to meet their needs. (NSW Ministry of Health (2012); Katterl & Bywood, 2011.)
- Are at increased risk of developing mental illness. 57% of people with intellectual disability under 65 also experience some form of psychiatric disability (AIHW, 2008). Research suggests up to 41% of adults with intellectual disability engage in self-harming behaviour. People at increased risk of self-harm and suicide are those limited verbal communication ability, vision or hearing impairments, dual diagnosis of mental illness and intellectual disability, or who misuse alcohol and other drugs (Murray 2003). Signs of mental illness are often missed (UIDH, 2011).
- Whilst people with intellectual disability are less likely to use substances, those who do are more likely to abuse substances (Didden, Embregts, van der Toorn & Laarhoven, 2009).

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Topic 4. Lived Experience: Personal Functioning and Communication

1. PERSONAL FUNCTIONING AND COMMUNICATION DIFFICULTIES

People with intellectual disability can experience personal functioning and communication difficulties as a result of intellectual impairment. These commonly include:

- **Difficulty with language, literacy and numeracy tasks.** For example, comprehending signs, reading clocks, bus/rail timetables or written instructions.
- **Difficulty with short-term memory and sequencing.** For example, people may forget information and instructions that aren't written down; they may find it difficult to work out how to travel on the train to a new destination; and they may need support to plan the steps to achieve a goal.
- **Difficulty understanding time and time management.** Time can be a difficult concept for people with intellectual disability. They may not understand the difference between am and pm; or quarter to and quarter past the hour; and may have difficulty with dates and concepts such as "two days ago". People with intellectual disability may have difficulty with time management. They may have trouble keeping appointments or getting to work on time (they may be late or early). They may struggle to work out how long it takes to get somewhere. To assist people to understand time or to describe time, connect time to something meaningful to the person – for example, was it "before or after dinner", "what was on television at the time?"
- **Difficulty with planning and problem solving tasks.** People with intellectual disability may have difficulty working through problems as they present themselves, such as a public transport-delay.
- **Difficulty recognising and responding to the feelings of others.** Understanding emotions can be challenging for people with intellectual disability. The language used to describe emotions is abstract, while the experience of emotions can be very concrete. People with intellectual disability often experience intense physical or behavioural responses to unexpressed emotions due to their limited means for identifying and expressing feelings. This is often compounded by a high level of experience of trauma through abuse and exploitation.

- **Difficulty with abstract thought.** PWID can have difficulty with abstract concepts. These relate to things can't be seen or touched, including mathematical concepts such as time and money; metaphors, euphemisms and analogies; emotions and feelings; humour and jokes. People with intellectual disability often have trouble understanding concepts such as rights, respect, confidentiality and goals. Commonly used terms like depression need to be explained. On the other hand, some people demonstrate a surprising understanding of complex concepts. For example, WWILD counselling clients with intellectual disability have coined the following phrases - "*thinking backwards*" (to describe flashbacks); "*eating my feelings*" (describing an eating disorder); and "*having trouble being a man*" (when talking about perpetrators of domestic violence).

2. PERSONAL FUNCTIONING AND COMMUNICATION DIFFERENCES

Intellectual impairment affects the way people think and learn, and people with intellectual disability may demonstrate different ways of learning; thinking; and navigating communication and social situations.

- **Learning differently.** Intellectual disability affects the way that a person learns. PWID will generally learn at a slower pace (and many people will describe themselves as being a 'slow learner'). This includes:
 - The time taken to learn something
 - The ability to read and write
 - Communication and understanding
 - The ability to plan and solve problems
 - The ability to adapt to new and/or unfamiliar situations (Intellectual Disability Rights Service, 2009).
- **A literal or "black & white" way of thinking.** Many people with intellectual disability are highly concrete thinkers. This can result in misunderstandings in interpersonal relationships due to their literal interpretation of verbal communication – for example, people may take humour and sarcasm literally.
- **Suggestibility.** People with intellectual disability can be easily suggestible (or ready to adopt the ideas of other people). This can be the result of difficulty understanding complex ideas, coupled with learned reliance and/or trust of other people for support. As a result, people with intellectual disability can be vulnerable to people taking advantage of them. For

example, signing contracts from a door to door sales person that they don't understand; or being "ripped off" in financial arrangements with friends and acquaintances.

- **Confabulation or "Exotic Story Telling".** Confabulation or 'exotic story telling' is a common technique used by people with intellectual disability to gain respect and approval from others. The stories they tell are often a reflection of the way the person wants to be seen, and are a means of increasing other people's opinions of them. Remember that people who confabulate are not deliberately lying, but are trying to impress.
- **Masking.** People with intellectual disability may internalise negative social attitudes and feel ashamed or embarrassed at having difficulty learning or managing daily living tasks. In turn, they may mask their difficulties:
 - To fit in and avoid the stigma associated with having a disability;
 - To avoid feelings of embarrassment and/or shame at not knowing or understanding;
 - To avoid being perceived as (or feeling) 'stupid'.
 - To avoid restrictions on opportunities to have the same experiences as peers, friends and family.
 - To avoid (further) experiences of mistreatment or abuse, including rejection, bullying, exploitation and abuse.

Masking can take different forms. Some people will not identify themselves as having an intellectual disability. They may not acknowledge or want to discuss any difficulties they experience. Some people develop strategies to hide limitations they experience, for example:

- Rote learning statements to use in conversation and/or to get by and deal with everyday experiences – for example "I don't know whether I'm Arthur or Marthur";
 - Avoiding tasks that are difficult – for example, paying for purchases with notes, rather than counting out coins; walking someone to a location, rather than giving directions.
- **Compliance (also called acquiescence) is a common method of masking disability.** It is very common for people with intellectual disability to take on a passive communication style, where they let the more powerful person in the conversation take the lead. People may adopt a compliant or acquiescent communication style because:
 - They do not understand what is said, so agree in an attempt to cover their misunderstanding/confusion.
 - They find it difficult to understand abstract information (we assume a lot of communication is straightforward, when in fact it involves a lot of abstract knowledge).

- They find it difficult to say no, particularly to someone in perceived authority.
- They are afraid to say no, and agree with what is said to avoid getting into trouble.

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Topic 5. Addressing the Communication Barrier

“Sometimes people with disability need time to say things about what they want. They can’t do the fast thing.” (WWILD Client)

Good communication with a person with an intellectual disability can be achieved by:

1. Adopting a person-centred approach

- Make sure you have the person’s attention. Minimise distractions.
- Use the person’s language. Be prepared to adjust your communication style.
- Encourage free recall – let the person tell their story.
- Try not to interrupt. Don’t finish the person’s sentences.
- Breaks are essential – the person is likely to have limited concentration.
- Adults with intellectual disability must be seen as adults. Do not speak to adults with an ID as if they are children.
- Taking the time to build rapport with a person with intellectual disability is essential to gaining trust and understanding how best to communicate with that person.

2. Using concrete language

- Use short sentences, simple language. Avoid complex words and jargon.
- Use open questions. Ask questions such as ‘Who?’, ‘When?’, ‘Where?’ and ‘What happened?’. ‘Why?’ is often more difficult.
- Signpost conversations. Let the person know if you are changing the topic or starting again. For example, you might say, “OK, that’s all I need to know about your home. Now can we talk about your family...”
- Reinforce the important messages. Summarise key points at the end of the conversation.

3. Allowing time

- Take your time. Explain things slowly, bit by bit. Don’t rush.
- Discuss one idea at a time. Don’t bombard people with too much information at once.
- Allow time for people to process information. Be prepared to wait. With some people you may need to wait an uncomfortable time to make sure there has been time for the person to process the information and answer.

4. Checking understanding.

- Give people permission to say “I don’t get it”. Acknowledge that this is hard stuff. For example, a worker could say, “I need to make sure I explain it properly. Please tell me if I’m not clear enough”.
- If the person doesn’t understand you, try different words and/or methods. Simple drawings or diagrams may be helpful.
- If you have trouble understanding the person – tell them and ask them to tell you again.

5. Being observant

- Observe the person’s behaviour, body language and facial expression as these may be saying something very different to their words. For example, someone might say they understand, but they may look anxious and confused.
- Be aware of masking behaviours. Many people with an intellectual disability will try to bluff their way through a conversation rather than saying they don’t understand; or they may indicate agreement when they don’t understand or agree. Remember “Yes doesn’t always mean yes”. Check that the person understands – but own the checking or the person may think they gave you the wrong answer, and may change their answer. For example, you could say, “I just want to check that I have explained this properly”.
- Be mindful of compliance. Avoid closed questions with “yes/no” answers. Open and concrete questions are best. For example, instead of asking “Do you remember when the doctor’s appointment is?”, it would be better to ask “Can you remind me when your doctor’s appointment is?”

In conclusion

It is important to remember that people with intellectual disability are not an homogenous group, and communication styles will differ from person to person. Some people will be articulate while others will have limited verbal skills and/or speech impairment. IQ is not a useful indicator of a person’s communication abilities. As a service provider or support person, you will need to get to know the person you are working with. This is best done by spending time with them. You may also consider engaging with people who know the person well to build your understanding of the person’s individual communication style and needs.

Remember -

“It is not the person’s job to understand you; it is your job to understand the person”.

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Topic 6. Lived Experience: Navigating Everyday Life

1. **COMPLEX NEEDS**

People with an intellectual disability experience complex needs associated with the combination of personal functioning and communication needs, and social experiences of living with intellectual disability (including disadvantage and stigma). Many people with intellectual disability experience some or all of the following:

- High levels of stress, anxiety and frustration, often resulting in “challenging behaviour”; self – harming; and/or mental illness.
- Poor self-esteem and a feeling of being judged, laughed at and ridiculed;
- Feelings and experiences of fearfulness, powerlessness and helplessness;
- High levels of dependency and thinking that others control their lives, including their choices and their bodies;
- Isolation and exclusion from meaningful relationship and valued social roles.

2. **EVERYDAY LIFE EXPERIENCES**

To understand some of the complexities of everyday life for people with intellectual disability, let’s look at some common experiences in living situations, relationships and service systems.

i. **Living situations**

It is extremely important to be aware of a person’s living situation when working with client’s with intellectual disability. The impact of a person’s living situation on their well-being is as significant for people with an intellectual disability as it is for anyone else. In fact, the security and appropriateness of a person’s accommodation can impact more significantly on a person who has an intellectual disability because they may find it harder to negotiate housing challenges (such as difficult neighbours or inaccessibility to transport). Issues in a person’s living situation may be related to personal functioning challenges associated with their disability, or to multiple social disadvantages that people with intellectual disability often experience, such as poverty, discrimination, and social isolation.

The vast majority of adults with intellectual disability living independently in the community, and do so without service support. People may live alone or in shared housing; with friends or family members; or in supported accommodation or a ‘group home’. 2012 ABS data shows:

- 82% of people with intellectual disability living in households, compared to 16% in “establishments” (for example, hospitals and nursing homes).

- 66% of people were living in a family household. Three quarters of these individuals were younger people aged between 0-34 years.
- Approximately 15% of people lived alone. These people are more likely to be older than those living in family households
- 3% of people with intellectual disability were living in a group household.

Research demonstrates people with an intellectual disability are at increased risk of homelessness (Oakes & Davies, 2008). Experiences of homelessness are often inter-related with other risk factors such as:

- Involvement in the CJS
- Alcohol and other drug use
- Poverty
- Poor physical and mental health
- Difficulty managing verbal communication
- Lack of appropriate education and employment opportunities
- Exploitation and abuse
- Social isolation

ii. Relationships

Relationships have an enormous influence in the lives of people with an intellectual disability. They have the potential to protect and support as well as to harm and create risk.

Many people with intellectual disability experience restricted social networks. They may have limited friendship experiences due to restricted participation in community life as a result of poverty, stigma, and difficulties with interpersonal relationships; they may have limited experience of workplace relationships due to difficulty accessing employment. However, most people have at least one significant adult person in their life, and it is important that support workers gain an understanding of a person's significant relationships where possible.

People with intellectual disability experience restricted opportunities for intimate partner relationships. People with intellectual disability often experience constraints on their right to engage in in sexual relationships, as a result of negative attitudes about the sexuality of people with intellectual disability and/or concerns about pregnancy and risk of abuse. Research demonstrates people may conduct their sexual lives in secret, paradoxically increasing their risk of exploitation and abuse (Johnson, Hillier, Harrison & Frawley, 2001).

People with intellectual disability may be discouraged or prevented from entering intimate partner relationships, co-habiting or marrying, or having children. Parents with intellectual disability are more likely to become involved in the child protection system and have their children removed from their care.

Many people with intellectual disability experience exploitation and abuse in relationships. As in the general population, sexual assault is most likely to be perpetrated by a known person, in a familiar location (home or workplace). A range of factors contribute to the vulnerability of people with intellectual disability to exploitation and abuse in relationships, including:

- Difficulties understanding the complicated and abstract nature of intimacy and relationships
- Limited knowledge and understanding of sex and sexuality
- Socialisation of people with intellectual disability to be compliant and accepting of decision making and control by other people.

People with intellectual disability who are socially isolated and in financial distress may be vulnerable to sexual exploitation to meet every day needs, for example, food, accommodation, cigarettes, transport.

iii. Involvement with multiple service systems

People with intellectual disability are often involved with multiple service systems, associated with experiences of social disadvantage. Involvement in multiple service systems can present challenges for people with intellectual disability, including understanding multiple support services and systems, understanding the relationship between systems, finding support and connection outside systems, falling through the gaps between systems, and reduced self-determination and personal development as result of heavily serviced lives.

Criminal Justice System

People with intellectual disability are over-represented as suspects or alleged offenders in the criminal justice system (French, 2007; Hayes, 2000). Offenders with intellectual disability are more likely to commit relatively minor offences, but to commit these repeatedly; and are more likely to be charged with public order offences (French, 2007). Estimates suggest up to 35% of young people in juvenile justice detention in Australia experience an intellectual disability in the mild to moderate range (West, 2011).

Child Protection System

People with intellectual disability are over-represented in child protection systems, both as parents and as children and young people in out-of-home care.

Parents with intellectual disability are more likely to have their children removed into out-of-home care (Booth, Booth & McConnell, 2005). However, there is no evidence that parents with intellectual disability are any more likely to abuse their children than any other parents (Lamont & Blomfield, 2009). Discrimination against parents with intellectual disability and lack of appropriate supports contribute significantly to the over-representation of parents with intellectual disability in the child protection system (Lamont & Bromfield, 2010).

Children and young people with intellectual disability are more likely to experience violence and abuse (Horner-Johnson & Drum, 2006) and are over-represented in out-of-home care (Raman, Inder & Forbes, 2005). Young people with intellectual disability exiting out-of-home care face an increased risk of poor adult life outcomes facing all care leavers, as a result of experiences of trauma in birth family and a lack of specialist support in or exiting out-of-home care (Jackson, O'Connor & Chenoweth, 2006; Mendes & Snow, 2014).

Health System

Despite higher levels of health care need, people with intellectual disability often have reduced or impeded access to health care services (Lennox & Edwards, 2001) and experience significantly worse health outcomes and lower life expectancies as a result (Lennox & Simpson, 2011).

A study by Lennox, Diggins and Ugoni (1997) identified five main barriers to providing health care to people with an ID:

1. Communication issues
2. Poor history taking
3. Poor compliance with health care plans
4. A lack of knowledge of common illnesses (experienced by people with an ID)
5. Consultation time restraints

Mental Health

People with intellectual disability may experience reduced capacity to participate in standard clinical assessment processes, which can make diagnosis difficult and restrict access to appropriate mental health care (White et al., 2005).

Social Welfare System

The majority of people with intellectual disability receive social welfare services. These may include:

- Public Housing (accommodation)
- Centrelink (income support, most commonly Disability Support Pension)
- Office of the Public Guardian (personal and health care decision making)
- Public Trustee (financial management).

People with ID often need support to access, understand and comply with the requirements of social welfare services, including support to complete paperwork, attend appointments, and understand and meet obligations.

Practice tip: Sometimes information that a person received the DSP and/or is subject to Public Guardian or Public Trustee orders may be an initial indicator that a person has an intellectual disability. Respectfully and sensitively asking people why they receive this payment and/or are subject to these orders can provide an opening for them to discuss their experience of intellectual disability.

iv. Decision Making

The presence of intellectual impairment does not mean a person cannot make decisions. People with intellectual disability can express their likes and dislikes, needs and wants, and make decisions and choices about their lives just like anyone else. It is essential that people involved in the support of a person with an intellectual disability understand the individual well enough to know how they best communicate these preferences. This can be challenging and requires time and commitment to building a good relationship with the person and others who know them well.

Some people with intellectual disability may need support (occasionally or regularly) to make decisions about their lives and personal affairs. For many people, decision-making support is provided 'informally' by the significant people in their lives, including family members, partners, friends, and service providers.

Some people with intellectual disability receive formal decision-making support from a legally appointed guardian. In Queensland, guardians are appointed by the Queensland Civil and Administration Tribunal (QCAT). Family members, close friends, professionals or anyone with a genuine and continuing interest in the welfare of an adult with impaired decision making capacity can apply to be appointed as a guardian. Guardians must be over 18 years of age and not a paid

carer for the adult (that is, not receiving remuneration other than a carer payment or Government benefit payment). A Public Guardian may be appointed where there is no one close to the adult who is willing to accept the responsibility of being their guardian, or there is a dispute about who should act as guardian, or a concern about the suitability or competence of a proposed guardian. Guardians are given the legal authority to make decisions on behalf of the adult such as:

- where they live
- what support services they receive
- with whom they have contact or visits
- general health care matters
- the approval of chemical, physical or mechanical restraint
- the approval of containment and seclusion in certain limited circumstances
- restricting access to objects
- other day to day issues.
- If the adult can communicate their views and wishes guardians should take these into account when making any decisions (QCAT, 2015).

When working with a person with intellectual disability, it is important to learn about any decision-making supports in the person's life - both informal and formal. It may be important to engage decision-making supports during the course of your work with a person, but always seek their permission before you do this and advocate for and support their involvement in decision-making processes. Where a person with intellectual disability does not have any decision making supports, but their lived experiences suggest these could help the person to better achieve their hopes, dreams, and personal well-being, service providers and supporters are encouraged to talk with the person about their choices and preferences, and explore the types of decision-making support that could be helpful to them. Wherever possible, supported decision making (supporting the person to consider options, weigh potential consequences, and make their own choice) is preferable to substitute-decision making (making decisions on behalf of another person).

The NSW Intellectual Disability Rights Service (Fogarty, 2009) advises the following principles should guide the use of decision-making support with people with intellectual disability –

- The wishes, opinions and choices of the person must always be sought and considered first;
- The privacy, cultural diversity and integrity of the person must always be respected;
- The least restrictive and intrusive intervention into the person's life;

- The ability to make decisions ('legal capacity') is a fluid concept that may vary from time to time and from decision to decision
- Diminished decision-making ability should not be confused with difficulties or impairment in communication – people should be provided adjustments and alternative modes of communication to express themselves;
- Substitute decision-making as an absolute last resort;
- Records must always be kept about supported and substitute decision-making arrangements and decisions made to ensure processes are transparent, subject to independent review and (if necessary) to appellate review by courts;
- Informal arrangements and support from family members, carers or friends who have close and continuing relationships with the person are preferable to formal orders of guardianship and financial management, and
- Support provided to the person to make decisions must always be in the best interests and welfare of the person.

3. SUPPORTING A GOOD LIFE

Topic 6 has focused on some of the everyday life complexities and challenges experienced by people with intellectual disability. However, it is important to remember the main aim of our work is to support people with intellectual disability to enjoy meaningful and fulfilling lives, including participation in valued roles (for example, paid work and parenting); having positive relationships with family, friends, colleagues and community members; living in accommodation of their choosing, either alone or with flatmates of their choosing; and healing from past experiences of trauma and abuse where these have occurred.

To support a person with intellectual disability to live a good life of their choosing, it is important for service providers and support people to build a strong relationship with the person and get to know what their hopes and dreams are, along with their fears and challenges. It is also helpful to get to know the important people in their life. From a base of deep knowledge of the person's goals and needs; and with the right supports developed and implemented; people with intellectual disability can navigate the complexities of everyday life; and may find some of the complexity is removed all together.

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