



# Report to the Office of the Senior Practitioner

## Mental Disorders in Intellectual Disability Survey and Training Workshops

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

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## Executive Summary

Intellectual disability affects approximately 1.8% of the Australian population. People with intellectual disabilities are at increased risk for the development of mental disorders, and are less likely than other Australians to receive appropriate treatment when this occurs. At the same time, mental health staff report feeling poorly equipped to care for people with intellectual disabilities and mental disorders.

In 2010, the Chair of Intellectual Disability Mental Health, School of Psychiatry, Faculty of Medicine, University of New South Wales instigated an educational project aiming to examine and respond to staff attitudes and training needs in this area. This project was undertaken within the Chair's Department of Developmental Disability Neuropsychiatry.

A research survey was developed to assess mental health staff confidence, attitudes and learning needs in Intellectual Disability Mental Health. Implemented primarily online, 222 South Eastern Sydney Illawarra Area Health Service staff completed the survey. Attitudes were found to be largely positive, inclusive and empowering, and demonstrated an appreciation of the underlying similarities between respondents and people with intellectual disabilities. Respondents believed people with intellectual disabilities should have the same access to their services as people without intellectual disabilities. Yet respondents also believed their services have difficulty meeting the needs of people with intellectual disabilities, and close to half did not think that people with intellectual disabilities and mental disorders should be treated in mainstream mental health services. Up to 60% of respondents were less confident in their professional skills with adults with intellectual disabilities, and more than half were not confident in referring to and liaising with Ageing, Disability and Home Care. The survey demonstrated a strong need for further training in intellectual disability mental health, with 80% of respondents indicating their current level of training in mental disorders in intellectual disability is inadequate, and 88% seeking more training in this field.

A two-day training curriculum was designed to meet some of the learning needs of mental health clinicians in the area of mental disorders in intellectual disability. Ten modules were developed, and divided into a "Fundamentals" and an "Advanced" full-day workshop. A range of presenters with relevant expertise from various organisations, including six from Ageing, Disability and Home Care, and three with intellectual disabilities, delivered the modules. Sixty-four clinical mental health staff attended the workshops at three South Eastern Sydney Illawarra Area Health Service sites. Formal workshop evaluation showed a high level of satisfaction with the modules and the presenters. Workshop participants completed the survey a second time to evaluate the six-month impact of the workshops on their confidence, attitudes and learning needs. These results will be published in peer-reviewed journals later in the year.

The project confirms that community mental health staff require support to develop their knowledge, skills and confidence in all areas of intellectual disability mental health. Formal, structured education and training is an important and effective means to assisting staff to improve their ability to provide mental health services to adults with intellectual disabilities. Contacts arising through the project revealed a strong demand for further education across diverse organisations in the intellectual disability, health and mental health sectors. Further efforts are required to develop and refine sustainable, flexible, and readily accessible educational materials in this field.

## Acknowledgements

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The views expressed in this document are those of the Department of Developmental Disability Neuropsychiatry, UNSW, and are not necessarily shared by the NSW Department of Family and Community Services (Ageing, Disability and Home Care).

## Background

### Prevalence

Intellectual disability (ID) affects approximately 1.8% of the Australian population (AIHW, 2003). People with ID have a disproportionately high prevalence of mental disorders when compared with the general population. Prevalence studies can be difficult to compare because of differing methodology, including the use of different sampling methods, diagnostic tools and diagnostic timeframes. Australian research has found lifetime prevalence rates of mental disorder in people with ID of 31.7% (Morgan, Leonard, Bourke, & Jablensky, 2008) and a point prevalence of 40.7% in children with ID (Einfeld & Tonge, 1996; Einfeld et al., 2006). The former figure of 31.7% is likely to under-estimate lifetime prevalence, as this data was drawn entirely from intellectually disabled mental health service users rather than a representative, population-based sample. One of the most robust studies of prevalence comes from a study in the United Kingdom which reported a point prevalence of 40.9% for any mental disorder in a population-based sample of adults with an ID (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). The 1-month and 12-month prevalence of any mental disorder in Australian adults without ID was recently reported as 10% and 20% respectively (Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). The figures indicate a disproportionately high rate of mental disorders in people with ID, relative to that observed in the general population.

### Treatment access and quality

Access to appropriate treatment for mental disorders for Australians with ID appears suboptimal. For example, within a ten year period, only 10% of Einfeld and Tonge's sample received any kind of mental health intervention (Einfeld & Tonge, 1996; Einfeld et al., 2006). In the UK, only 15% of older adults with ID and a psychiatric disorder are known to mental health services (Patel, Goldberg, & Moss, 1993). These findings contrast with recent data in people without ID which documented that 34.9% of Australians with mental disorders received treatment within a 12 month period (Slade et al., 2009).

Not only do people with ID experience higher rates of mental disorder and a lower rate of treatment, research suggests that services are ill equipped to meet the needs of people with ID (Torr et al., 2008; Hassiotis, Barron, & O'Hara, 2000). Australian GPs and psychiatrists do not believe they are adequately trained to understand, assess and treat mental disorders and behavioural problems in adults with ID (Cook & Lennox, 2000; Edwards, Lennox, & White, 2007; Jess et al., 2008; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996; Lennox, Diggins, & Ugoni, 1997; Phillips, Morrison, & Davis, 2004; Torr et al., 2008). Psychiatrists are less confident in dealing with this patient group than their UK counterparts (Jess et al., 2008), and believe patients with ID receive a relatively poor standard of care (Edwards et al., 2007; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996).

The mental health and behavioural issues that face adults with ID are more complex than those facing adults without ID. In part, this is due to the heterogeneity of this group (Bouras & Holt, 2004), and the diverse ways ID can manifest and affect an individual's life and health. To be effective and confident in treating adults with mental disorder and ID, clinicians require specialised knowledge and skills. There is a general perception that training in intellectual disability mental health (IDMH) is inadequate (Edwards et al., 2007; Mohr, Phillips, Curran, & Rymill, 2002; Torr et al., 2008), and GPs

and psychiatrists alike express an interest in further education in this area (Lennox & Chaplin, 1995; Lennox & Chaplin, 1996; Phillips et al., 2004). Indeed, targeted training of mental health professionals appears to be effective in increasing confidence, skills, knowledge and attitudes in this area (Mohr et al., 2002).

Specialised services for people with ID and mental disorders are very limited and isolated to a small number of tertiary or quaternary services. Therefore, the responsibility for provision of publically funded specialist mental health services for people with ID falls on the generic mental health service. In this setting, community and inpatient mental health staff will inevitably come into contact with people with ID. Anecdotally, mental health staff report feeling less confident in providing care to clients with an ID, and feel particularly challenged by the complexity involved in assessing individuals with communication impairments and multiple disabilities. This echoes the formal research cited above, and lends support to the need for education and training endeavours to address the situation.

### Staff confidence and ability

In an effort to initiate an improvement in the access to and quality of health care for adults with ID in NSW, the NSW Department of Family and Community Services (Ageing, Disability and Home Care) (ADHC) in 2010 granted \$45,028.18 to the Department of Developmental Disability (3DN), UNSW, to fund a project addressing the educational needs of community mental health staff within the former South Eastern Sydney Illawarra Health Service (SESIAHS). The proposed work had two distinct components: the development and implementation of a survey, and the development and implementation of a training workshop for IDMH within the former South Eastern Sydney Illawarra Area Health Service. Each of these components is described separately in the body of this report.

## The Survey

### Aims

This project involved developing and implementing a survey of attitudes, confidence and learning needs regarding mental disorders in adults with ID. The purpose of the survey was to gain a deeper insight into factors that may be affecting the broader capacity of SESIAHS mental health services to meet the mental health needs of adults with ID and to provide a means of evaluating the impact of a series of training workshops which were subsequently implemented within this Area Health Service.

### Method

#### Development

A survey was designed to assess attitudes, training needs, confidence, and various demographic and professional variables. A component of the survey employed the widely used *Community Living Attitudes Scale (CLAS) – Short Form* (Henry, Keys, & Jopp, 1998), a validated questionnaire assessing four dimensions of attitudes towards people with ID – Empowerment, Exclusion, Sheltering, and Similarity. Other questions were developed specifically for this project, as a thorough literature search revealed no suitable questions or instruments we could use (see Appendix 1 for the full survey). The survey was piloted with a small group of mental health staff from another Area Health Service, and feedback concerning readability and ease of use was considered in drafting the final version.

Ethics approval for the survey was granted by the SESIAHS Human Research Ethics Committee (HREC) – Southern Hospitals Network, the lead HREC covering the Northern, Central and Southern Networks (Approval number HE10/184).

#### Implementation

To publicise the survey, Mental Health Service Directors were asked to forward at least three emails to their staff over a period of five weeks. The emails invited all mental health service staff at all levels of seniority, both administrative and clinical, to complete the survey.

The survey was made available to complete either online within the SESIAHS Intranet environment (using Key Survey software), or by printing a paper-version and returning it by fax or mail. Surveys were completed anonymously. However, in order to link repeated surveys for those attending the workshop series, respondents created a unique code using selected alphanumeric symbols from their names, phone numbers, and to denote sex and location (see Appendix I, p 29). This coding system also acted as a method of detecting duplicate surveys, in instances where a respondent had returned the survey by more than one method.

Workshop participants were asked to complete the survey a second time, six months after their last workshop, in order to assess the long term impact of the workshops on attitudes, confidence, and training needs.

## Results

The results of the first survey of SESIAHS mental health staff are reported below. As data analysis for the 6-month post-workshop survey is not yet complete, these results will be published separately, in peer-reviewed scientific journals.

### Sample characteristics

Of approximately 1000 staff who were invited to complete the survey, 222 responded, a response rate of 22%. The majority of respondents were female (156; 75%; n=207), and English was their most fluent language (210; 95%; n=222). The majority had completed university studies to Bachelor (79; 36%) or post-graduate (107; 48%) level, while the highest level of education for the remaining was TAFE (12; 5%), High School (7; 3%), or 'other' (eg diplomas, certificates etc; 17; 8%) (n=222).

Most respondents were mental health professionals performing a clinical role (Table 1). Respondents had substantial personal or professional contact with people with ID (71%; Table 2), and approximately one quarter (27%) had professional contact with an adult with an ID at least weekly (Table 3). More than half (52%) had professional contact at least once a month.

**Table 1 Main Role and occupation of Survey Respondents**

Main Role	n	%
Administration	15	6.8
Clinical	169	76.1
Education	7	3.2
Managerial	17	7.7
Other (eg combined clinical/managerial, clinical/education)	14	6.3
Total	222	100.0
<b>Occupation</b>		
Admin – with patient/client contact	12	5.4
Admin – without patient/client contact	3	1.4
Occupational Therapist	22	9.9
Nurse (all)	71	32.0
Psychiatrist	24	10.8
Psychologist (all)	46	20.7
Social worker	25	11.3
Other (eg counsellor, registrar, research assistant etc)	19	8.6
Total	222	100.0

**Table 2 Current or previous Close Contact with an Adult with Intellectual Disability**

	Close Personal	Close Professional	Any close contact
Yes	93 (41.9 %)	121 (54.8%)	158 (71.0%)
No	129 (58.1%)	100 (45.2%)	64 (29.0%)
Total	222 (100.0%)	221 (100.0%)	222 (100.0%)

**Table 3 Frequency of Professional Contact with Adults with Intellectual Disabilities**

	Daily	Weekly	Once/month	Once/3 months	<Once/3 months	Never
n (%)	17 (7.7%)	43 (19.4%)	55 (24.8%)	40 (18.0%)	56 (25.2%)	11 (5.0%)
cumulative	17 (7.7%)	60 (27.0%)	115 (51.8%)	155 (69.8%)	211 (95.0%)	222 (100.0%)



## Attitudes, Learning Needs and Confidence

On the whole, respondents showed very positive attitudes towards people with ID. The Community Living Attitudes Scale items are scored from 1 (Strongly Disagree) to 6 (Strongly Agree). The results (Table 4) revealed a reasonably strong attitude that people with ID should be included in community life (indicated in the *Exclusion* subscale scores), and a strong sense that people with ID share a common humanity with others in society (indicated in the *Similarity* subscale scores). The *Empowerment* and *Sheltering* subscales revealed more variation in attitudes, but respondents tended to agree that people with ID (irrespective of level of disability) should have the power to make decisions about their own lives, and generally disagreed that people with ID require protection from the dangers of life in the community.

Table 5 displays data about respondents' attitudes towards people with ID relating to their own services, and about perceived learning needs. There was overwhelming agreement that people with ID should have the same access to their services as people without ID, though more than two-thirds of respondents believed their services had difficulty managing people with ID. Results reveal a strong sense that current training is inadequate, and a high level of interest in further training.

Table 6 reports respondents' comparisons between their confidence involving intellectually disabled versus non-intellectually disabled adults in the same contexts. Between 11% and 13% of respondents felt *more* confident when dealing with adults with ID in each of the contexts. There was greater variation in the proportion of respondents who were equally- or less-confident in situations involving adults with ID. More than half of respondents were less confident in understanding and applying considerations around guardianship and consent, in communicating, in understanding potential adverse effects of medication, and in understanding the relationship between behavioural problems and mental disorders. Around 13% of respondents indicated they were "much" less confident in applying considerations around guardianship and consent, and in understanding the potential adverse effects of medications. Yet close to half felt confident they were able to provide the same general level of service to adults with ID as to non-disabled adults, and on each of the other measures around a third reported feeling equally confident.

**Table 4 Community Living Attitudes Scale Mental Retardation (CLAS-MR) – Short Form**

Subscales and items		n	Mean	SD	% disagree	% agree
<b>Empowerment</b>		<b>221</b>	<b>4.7</b>	<b>0.8</b>	<b>NA</b>	<b>NA</b>
	1. People with intellectual disabilities should not be allowed to marry and have children (R).	219	5.1	1.1	11.0	89.0
	2. A person would be foolish to marry a person with an intellectual disability (R).	221	5.3	1.0	11.0	89.0
	3. People with intellectual disabilities can plan meetings and conferences without assistance from others.	220	4.1	1.3	28.2	71.8
	4. People with intellectual disabilities can be trusted to handle money responsibly.	220	4.5	1.2	15.5	84.5
	5. The opinion of a person with an intellectual disability should carry more weight than those of family members and professionals in decisions affecting that person.	220	4.2	1.3	26.8	73.2
<b>Exclusion</b>		<b>222</b>	<b>1.3</b>	<b>0.5</b>	<b>NA</b>	<b>NA</b>
	7. Increased spending on programs for people with intellectual disabilities is a waste of tax dollars.	221	1.3	0.8	97.3	2.7
	8. Homes and services for people with intellectual disabilities downgrade the neighbourhoods they are in.	221	1.4	0.8	96.4	3.6
	9. People with intellectual disabilities are a burden to society.	221	1.5	0.9	95.0	5.0
	10. Homes and services for people with intellectual disabilities should be kept out of residential neighbourhoods	222	1.2	0.6	99.1	0.9
<b>Sheltering</b>		<b>221</b>	<b>3.0</b>	<b>0.9</b>	<b>NA</b>	<b>NA</b>
	6. Specific workplaces for people with intellectual disabilities are essential.	220	4.0	1.6	32.3	67.7
	11. People with intellectual disabilities need someone to plan their activities for them.	221	2.9	1.2	64.7	35.3
	16. People with intellectual disabilities should live in sheltered facilities because of the danger of life in the community.	220	2.0	1.2	86.4	13.6
	17. People with intellectual disabilities usually should be in group homes or other facilities where they can have the help and support of staff.	219	2.9	1.4	63.5	36.5
<b>Similarity</b>		<b>222</b>	<b>5.7</b>	<b>0.6</b>	<b>NA</b>	<b>NA</b>
	12. People with intellectual disabilities do not need to make choices about the things they will do each day (R).	221	5.6	0.7	1.4	98.6
	13. People with intellectual disabilities can be productive members of society.	222	5.7	0.8	1.4	98.6
	14. People with intellectual disabilities have goals for their lives like other people.	221	5.7	0.7	0.9	99.1
	15. People with intellectual disabilities can have close personal relationships just like everyone else.	222	5.7	0.7	0.9	99.1
R = Items reverse-scored to reflect their scale loadings. Subscales are scored by taking the mean of the responses to the items, resulting in a possible range of scores from 1 to 6.						

**Table 5 Learning Needs, Knowledge, Confidence and Attitudes**

	Disagree			Agree		
	Strongly (%)	Moderately (%)	Somewhat (%)	Somewhat (%)	Moderately (%)	Strongly (%)
Attitudes Regarding Mental health Services for Adults with Intellectual Disabilities						
Adults with ID and mental disorders should be treated in mainstream mental health services. (n=220)	11.8	14.5	19.1	19.5	18.2	16.8
	n=100 (45.5%)			120 (54.5%)		
Most adults with ID who contact our service have a behavioural problem rather than a mental disorder. (n=216)	21.3	25.9	20.4	24.1	7.4	0.9
	146 (67.6%)			70 (32.4%)		
Adults with ID and mental disorders should have the same access to our service as people without ID. (n=220)	2.7	1.4	1.8	9.1	14.5	70.5
	13 (5.9%)			207 (94.1%)		
Learning Needs, Knowledge & Confidence						
I would be interested in further training in mental health and disorders in adults with ID. (n=219)	3.2	4.6	4.6	11.9	19.2	56.6
	27 (12.3%)			192 (87.7%)		
I have had sufficient training regarding mental health and disorders in adults with ID. (n=220)	35.9	25.0	19.1	8.2	6.8	5.0
	173 (80.0%)			44 (20.0%)		
Adults with ID and mental disorders are more difficult for our service to manage. (n=220)	8.2%	7.3%	12.3%	36.8%	22.3%	13.2%
	61 (27.7%)			159 (72.3%)		
I can recognise when a patient/client may have an ID. (n=213)*	1.4	6.1	5.2	38.0	35.2	14.1
	27 (12.7%)			186 (87.3%)		
Mental disorders in adults with ID can be effectively treated. (n=203)**	0.5	0.5	3.4	21.7	36.9	36.9
	9 (4.4%)			194 (95.6%)		
I am confident referring to and liaising with ADHC. (n=206) **	10.7	16.5	24.3	20.9	15.0	12.6
	106 (51.5%)			100 (48.5%)		
* Administrative staff without direct contact to clients did not answer this question						
** Only clinical staff answered this question (no administrative staff)						

**Table 6 Relative Confidence in Clinical Interactions with Adults with Intellectual Disabilities**

	Less confident (%)			Equally (%)	More confident (%)		
	Much (%)	Moderately (%)	Slightly (%)		Slightly (%)	Moderately (%)	Much (%)
Provide the same general level of service. (n=217)	4.1	10.1	24.9	47.9	3.7	6.5	2.8
	39.1				13.0		
Understand and apply considerations around guardianship and consent. (n=218)	13.3	11.9	30.3	32.6	6.0	4.1	1.8
	55.5				11.9		
Communicate effectively – understanding and being understood. (n=218)	4.1	17.0	38.5	29.4	2.3	6.9	1.8
	59.6				11.0		
Understand potential adverse affects of psychotropic medication. (n=206)*	13.6	12.6	30.1	32.0	3.9	4.4	3.4
	56.3				11.7		
Identify when further assessment or treatment for a mental disorder is required. (n=207)*	4.8	13.5	24.6	44.0	4.3	3.9	4.8
	43.0				13.0		
Identify the risk factors for mental disorders. (n=205)*	2.9	12.7	29.8	43.4	2.0	4.4	4.9
	45.4				11.2		
Understand the relationship between behavioural problems and mental disorders. (n=207)*	6.3	15.0	34.8	31.4	6.3	2.9	3.4
	56.0				12.6		
* Only clinical staff answered this question (no administrative staff)							

## Discussion

The majority of survey respondents were highly educated, female, and had a clinical role. Respondents also reported a significant level of contact with adults with ID. Previous research has found that being educated (Jones, Ouellette-Kuntz, Vilela, & Brown, 2008; Yazbeck, McVilly, & Parmenter, 2004), female (Jones et al., 2008; Ouellette-Kuntz, Burge, Henry, Bradley, & Leichner, 2003), and having contact with people with ID (Horner-Johnson et al., 2002; Yazbeck et al., 2004) each have a positive impact on attitudes towards people with ID, and this is reflected in the attitude measures in the survey.

Overall respondents held positive, inclusive, empowering attitudes towards people with ID, particularly when compared with similar groups. Respondents tended towards more positive empowerment, inclusion and similarity attitudes than Canadian ID community staff (Jones et al., 2008) in terms of the proportion of the group who agreed with positive attitudes, and senior Canadian psychiatry registrars (Ouellette-Kuntz et al., 2003) in terms of the strength with which attitudes were held. This general positive attitude was also reflected in the overwhelming agreement that people with ID are entitled to the same access to respondents' services as people without ID, and that mental disorders in adults with ID can be effectively treated.

Interestingly, despite almost all respondents agreeing that adults with ID should have the same access to their service as non-disabled adults, only half agreed that adults with ID should be treated in mainstream mental health services. This may reflect an awareness that services are presently ill-equipped to meet the needs of people with ID, and is reminiscent of the finding that Australian psychiatrists do not believe that mainstream psychiatric inpatient services are suitable for adults with ID (Edwards et al., 2007; Jess et al., 2008; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996). The majority of respondents indicated that their services had difficulty managing people with ID, and relative confidence in providing care to people with ID was lower for a significant proportion of respondents, echoing previous findings in GPs (Cook & Lennox, 2000; Lennox et al., 1997) and psychiatrists (Jess et al., 2008). This was the case for all aspects of service delivery, but especially in the areas of communication, psychoactive medication, behavioural problems, and guardianship and consent.

A small but significant minority of respondents were *more* confident in providing mental health services to adults with ID than to adults without ID. This was unexpected, given anecdotal reports to the contrary during the planning stage of the project. Whether respondents' level of confidence reflects their actual competence is impossible to say from the current data. These figures may reflect the high level of contact with intellectually disabled adults reported by this survey group. However given the widely replicated finding that mental disorders are underdetected and undertreated in this population (Einfeld & Tonge, 1996; Einfeld et al., 2006; Patel, Goldberg, & Moss, 1993), respondents' confidence when it comes to detecting and understanding risks for mental disorder in this population may in fact indicate an overestimation of skill and ability. In fact, while one third of respondents believed that most people with ID contacted their services due to a behavioural rather than a mental health issue, more than half said they lacked confidence in understanding the relationship between behavioural problems and mental disorders, implying some confusion in this area.

Prior research has reported that Australian psychiatrists (Edwards et al., 2007; Jess et al., 2008; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996) and GPs (Cook & Lennox, 2000; Lennox et al., 1997; Phillips et al., 2004) believe their current level of training in ID is inadequate, and both groups consistently show an interest in accessing further training (Cook & Lennox, 2000; Edwards et al., 2007; Jess et al., 2008; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996; Lennox et al., 1997; Phillips et al., 2004). The sense that current training is insufficient and the interest in further training was unequivocally borne out in the current group. This is unsurprising, given respondents' positive attitudes towards people with ID together with their general relative lack of confidence in servicing this group.

The survey outcomes suggest that future training and education efforts should focus on all aspects of providing services to adults with ID and mental health needs. However it seems that the more complex aspects of providing mental health services are the areas where respondents most lacked confidence. Therefore areas of particular need, and which are incidentally fundamental to all aspects of mental health service delivery, are communication, the relationship between challenging behaviour and mental disorders, legal and ethical considerations, and the use of medication to manage mental disorders in adults with ID. Furthermore, half the clinicians were lacking confidence in referring to and liaising with ADHC. This highlights the need for provision of further specific information to assist mental health staff in their understanding of ADHC's role, referral process, and service contacts. Provision of such information, for example, in conjunction with the role out of the *Memorandum of Understanding and Guidelines in the Provision of Services to People with an Intellectual Disability and a Mental Illness* between ADHC and NSW Health, is likely to enhance inter-agency cooperation and collaboration.

## Limitations

The response rate (22%) recorded for the survey is at the lower end of the range that is customary for research of this type, and it is unclear whether our sample is representative of the entire SESIAHS mental health service. It is possible that the common factor increasing the likelihood of responding was a positive attitude towards people with ID (evident in the results), affecting motivation to complete the survey.

It is difficult to speculate about the reason for the low response rate. Even though survey completion took only five minutes, and was promoted thus, there was a significant amount of written material accompanying the emailed survey invitations. This was to satisfy the ethical requirements of conducting a survey, and it is possible that the large volume of accompanying information served as a barrier to busy staff.

Another possible reason for the low response rate is that staff may have lacked the motivation to complete a survey regarding ID. If this is indeed the case, it is possible that many non-responders possess negative, or at least apathetic, attitudes towards people with ID and their health care needs.

Future implementations of the survey may increase the response rate by engaging an intensive, persistent and targeted recruitment strategy.

## Next steps

The six-month follow up implementation of the survey is currently underway, with data collection completed in June 2011. The follow up survey data will be compared with responses from the first implementation of the survey to assess any impact of the workshops on confidence, attitudes and learning needs. The results will be published in peer-reviewed scientific journals.

## The Workshop

### Aims

This project involved developing and piloting a series of training workshops in IDMH for mental health staff within South Eastern Sydney Illawarra Area Health Service (SESAHS). The workshop curriculum and materials were designed to build skills, knowledge and confidence through a two-day program – the first (*Workshop 1: Fundamentals*) providing a thorough introduction to mental disorders in ID, and the second (*Workshop 2: Advanced*) providing greater depth of learning in specialised topics in the field. The program was piloted within SESAHS to evaluate its feasibility as a means to enhancing the capacity of community mental health and other similar services to respond to the mental health needs of people with ID.

### Method

#### Development of training material

A number of local and international institutions focus on research and education in ID health or mental health. To avoid duplication, we conducted a comprehensive search to identify training/education packages that could satisfy the requirements of this project, either wholly or in part. The quality of the materials sourced was extremely high, however none were suitable for direct application in this project, primarily because a two day workshop series could not accommodate the depth and duration of their modules:

- *Mental Health in Learning Disabilities: A Training Resource* (Estia Centre, <http://www.estiacentre.org/>). A comprehensive training package aimed at introducing mental health concepts to disability workers, with 18 modules each designed to be delivered over half- or full-day workshops (71 hours total). Unsuitable for experienced mental health clinicians, or for use in two single-day workshops
- *Mental Health in Adult Developmental Disability: An Education and Training Kit for Professionals and Service Providers* (Queensland Centre for Intellectual and Developmental Disability, University of Queensland). A comprehensive package of seven units (each comprising two-three modules) aimed at providing thorough training to a wide audience, including mental health clinicians. Units are designed to be delivered in half- and full-day workshops (32 hours in total), and while suitable for experienced mental health professionals, the units could not be accommodated within a two-day workshop series.
- *Health and Disability: Partnerships in Action* (Centre for Developmental Disability Health Victoria, Monash University). A self-directed learning CD-ROM supplemented by a text book, student workbook, tutor guide and detailed video vignettes. A comprehensive resource designed to give diverse health professionals a thorough understanding of health, healthcare, and mental health issues faced by people with developmental disabilities. An excellent resource, however unsuited for workshop-style delivery.

As none of the available resources were suitable for our purposes, we designed modules and a workshop program specifically for the project, following the process outlined below.

### *1. Topic Outline*

An outline of the broad subject areas that a sound introduction to mental disorders in ID should address formed the starting point for development of the curriculum. The list was based on the clinical, teaching and academic experience of the project team. The topic outline was compared with the modules in the educational resources reviewed above, and revisions were made to ensure all relevant information was included and organised coherently. The topics were ordered in a sequence that followed the logical structure of the information contained – eg “Management”, focusing on all aspects of managing mental disorders in adults with ID, requires an understanding of communication, assessment, and the agencies involved in supporting people with ID, and therefore followed the modules covering these subjects.

The result was a curriculum framework that served as the foundation for ten workshop modules:

1. Introduction to Intellectual Disability
2. Mental Disorders in ID – Introduction
3. Mental Disorders in ID – Communication and Assessment
4. Agencies Involved in Supporting People with Intellectual Disability
5. Mental Disorders in ID – Management
6. Mental Disorders in ID – Challenging Behaviour
7. Mental Disorders in ID – Legal and Ethical Issues
8. Mental Disorders in ID – Lifespan and Transition Issues
9. Mental Disorders in ID – Personality Disorders and Offending Behaviour
10. Mental Disorders in Other Developmental Disabilities

The modules were divided into a two-day program with the rationale that the first five modules represented essential learning for mastering the next five modules. Modules 1-5 formed the curriculum for *Workshop 1: Fundamentals*, and modules 6-10 formed the curriculum for *Workshop 2: Advanced*.

### *2. Learning Objectives, Knowledge and Skills*

Each topic was expanded to specify its learning objectives and the knowledge and skills that learners should gain by taking the module (see Appendix 2). This ensured that the learning materials for the module avoided overlap and were developed to be comprehensive and balanced.

### *3. Stakeholder consultation*

A series of face-to-face meetings with senior staff within each Network (Northern, Central and Southern) was used to seek feedback on the topics and learning objectives. Prior to meeting, staff from the level of director through to clinical manager were sent an outline of the project and the topics and learning objectives. The meetings were an opportunity to provide feedback on the proposed content and structure of the workshops, and advice about which areas of learning are perceived as priorities amongst staff.

The consultation process resulted in positive feedback and confirmed that the curriculum addressed areas of training need amongst clinicians.



#### 4. Information for presenters

Two documents were created to guide the development of workshop presentations and slides for each module. The first was an “Information Framework” (Appendix 3) which details all the specific points that a module should cover, and is similar to a tutor or facilitator guide. The second document (“Guidelines for Presenters”; Appendix 4) provided guidance for presentation style, duration, use of diverse media, and activities and methods of creating an interactive and engaging presentation.

#### Presenters

A range of guest presenters with relevant expertise were enlisted to run certain modules (see Appendix 5 for presenter biographies). Half the presenters (six in total) were from ADHC, showcasing the collaboration underlying the workshops and giving the Office a visible presence, as well as providing specialist knowledge across relevant learning areas. Presenters developed presentations and PowerPoint slides addressing all the learning points and information in the *Information Framework* document. Presenters also used a variety of modalities and interactive formats and activities in order to facilitate learning.

Three adults with ID from NSW Council for Intellectual Disability (NSW CID – the ADHC-funded body representing people with ID) were invited to give presentations at the workshops. Michael Bartels and Fiona McKenzie gave presentations during the module *Introduction to Intellectual Disability* in *Workshop 1: Fundamentals*, and Kim Walker developed a presentation for the module *Lifespan and Transition Issues* which a 3DN staff member gave on her behalf in *Workshop 2: Advanced*.

#### Implementation

All SESIAHS clinical adult mental health staff were eligible to attend, and the workshops were promoted via a series of emails forwarded by the network mental health directors. The department also met with clinical managers in each network to promote the workshops, and gave each network a promotional flyer to be displayed on noticeboards.

Given SESIAHS covers approximately 6333 square kilometres and spans a distance of more than 200km between Ulladulla and Sydney, the workshops were held at three sites in order to maximise the opportunity for all eligible staff to attend. Each workshop (*‘Fundamentals’* and *‘Advanced’*) was held once at Prince of Wales, St George, and Wollongong Hospitals. Participants were permitted to attend at any venue, and the period between Workshops 1 and 2 ranged from one to three months.

A condition of attending the workshops was agreement to complete the survey twice. Attending Workshop 1 was a prerequisite for attending Workshop 2; however participants could choose to attend Workshop 1 only.

The workshop program covered an entire day, with three breaks for morning tea, lunch and afternoon tea. The workshop program, presenter biographies, presentation slides, and activities were printed and bound in a workbook for participants.

## Evaluation

At the end of each workshop participants were asked to complete an evaluation form (Appendix 6) to obtain feedback and assess satisfaction with the workshop. Evaluation of learning outcomes from the workshop measured via the survey will be analysed in the coming months. The results will be compared with those of the pre-workshop survey to ascertain any enduring change in attitudes, confidence and learning needs following the workshop.

## Results

### Attendance

The workshops were well received, with 64 participants attending *Workshop 1: Fundamentals*, and 47 attending *Workshop 2: Advanced*. Site-specific attendance is detailed below:

**Table 7 Workshop Attendance**

	Workshop 1: Fundamentals	Workshop 2: Advanced
Prince of Wales Hospital	16	23
St George Hospital	26	13
Wollongong Hospital	22	11

The demographic profile of participants, and details of their roles and the teams they belong to will be available once the data analysis for the survey is complete.

### Evaluation

Participants evaluated both workshops very positively, rating both the individual modules and the presenters highly in the questionnaire they completed at the end of the day. General comments about the workshops included:

*"All very useful and relevant"*

*"Very appropriate to my skill and experience level"*

*"Interesting, informative and thorough"*

*"(it was) helpful to have practical tips for communication and assessing"*

*"Thank you so much, I have learnt a lot today"*

*"Straight to the point"*

*"Useful advice provided that can be directly applied in everyday practice"*

*"Every session was relevant to give a holistic fundamental training program"*

*"I learnt some strategies and attitudes that I can incorporate in my practice"*

*"Pitched at just the right level. Very interesting speakers"*

*"Looking forward to the advanced workshop later this year"*

*"Very enjoyable day"*

The evaluation form asked participants to rate various outcome measures, all using the following scale from 1 to 5:

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
1	2	3	4	5

### *Module and content ratings*

Participants rated the success of the workshop in improving knowledge and confidence in specific knowledge areas that corresponded to the content of each module (Table 8). For both Workshops 1 and 2 the average rating for every knowledge area was 4 (“good”).

Participants were also asked which modules were most- and least-useful, with the option of nominating none, one, or more than one in each category (see Table 9).

When asked how easy it was to understand the information in the workshop on the scale of 1 to 5, participants evaluated the workshops highly, with an average score of 4.59 for Workshop 1 and 4.33 for Workshop 2 (Table 10).

**Table 8 Workshop Evaluation Module and Content Ratings**

<b>Workshop 1: Fundamentals</b>	<b>POW</b>	<b>St George</b>	<b>Wollongong</b>	<b>ALL</b>
The health, social and psychological issues associated with intellectual disability	<b>mean: 4.13</b> range: (3 – 5) n=15	<b>4.29</b> (3 – 5) n=24	<b>4.19</b> (3 – 5) n=21	<b>4.22</b> (3 – 5) n=60
The complexity and variety of intellectual disability and its associated syndromes	<b>3.80</b> (3 – 5) n=15	<b>4.14</b> (3 – 5) n=22	<b>4.10</b> (3 – 5) n=21	<b>4.03</b> (3 – 5) n=58
The presentation of mental health problems in adults with an intellectual disability	<b>4.13</b> (3 – 5) n=15	<b>4.25</b> (3 – 5) n=24	<b>4.30</b> (3 – 5) n=20	<b>4.24</b> (3 – 5) n=59
Communication and assessment strategies for adults with intellectual disability and mental disorders	<b>4.27</b> (3 – 5) n=15	<b>4.33</b> (3 – 5) n=24	<b>4.42</b> (3 – 5) n=19	<b>4.34</b> (3 – 5) n=58
Clinical management of clients with intellectual disability and comorbid mental disorder	<b>4.36</b> (3 – 5) n=14	<b>4.26</b> (3 – 5) n=23	<b>4.11</b> (3 – 5) n=19	<b>4.23</b> (3 – 5) n=56
Referring to and working with ADHC and other associated agencies	<b>3.67</b> (3 – 5) n=15	<b>4.04</b> (2 – 5) n=24	<b>3.95</b> (3 – 5) n=20	<b>3.92</b> (2 – 5) n=59
<b>Mean</b>	<b>4.05</b>	<b>4.20</b>	<b>4.18</b>	<b>4.16</b>
<b>Workshop 2: Advanced</b>	<b>POW</b>	<b>St George</b>	<b>Wollongong</b>	<b>ALL</b>
Challenging behaviour in adults with intellectual disability and its relationship to mental disorders	<b>4.24</b> (3 – 5) n=21	<b>4.67</b> (4 – 5) n=12	<b>4.44</b> (4 – 5) n=9	<b>4.44</b> (3 – 5) n=42
Ethical and legal considerations when working with adults with intellectual disability and comorbid mental disorder	<b>4.05</b> (3 – 5) n=21	<b>4.67</b> (3 – 5) n=12	<b>3.89</b> (3 – 5) n=9	<b>4.19</b> (3 – 5) n=42
Lifespan and transition issues in adults with intellectual disability and comorbid mental disorder	<b>3.95</b> (3 – 5) n=20	<b>4.25</b> (3 – 5) n=12	<b>4.44</b> (4 – 5) n=9	<b>4.15</b> (3 – 5) n=41
Personality disorders, forensic and D&A issues associated with intellectual disability and comorbid mental disorder	<b>4.10</b> (2 – 5) n=21	<b>4.67</b> (4 – 5) n=12	<b>4.22</b> (3 – 5) n=9	<b>4.29</b> (2 – 5) n=42
Mental disorders in adults with other developmental disabilities	<b>4.19</b> (3 – 5) n=21	<b>4.78</b> (4 – 5) n=9	<b>4.33</b> (4 – 5) n=6	<b>4.36</b> (3 – 5) n=36
<b>Mean</b>	<b>4.11</b>	<b>4.58</b>	<b>4.27</b>	<b>4.28</b>

**Table 9 Most- and Least-Useful Modules**

<i>Workshop 1</i>	<b>Most useful</b>				<b>Least useful</b>			
	POW	St George	Wollongong	ALL	POW	St George	Wollongong	ALL
Introduction to Intellectual Disability	40.0%	8.3%	14.3%	<b>18.3%</b>	6.7%	0.0%	0.0%	<b>1.7%</b>
Mental Disorders in Intellectual Disability – Introduction	6.7%	12.5%	19.0%	<b>13.3%</b>	6.7%	12.5%	0.0%	<b>6.7%</b>
Communication and Assessment	40.0%	83.3%	45.9%	<b>58.3%</b>	6.7%	0.0%	0.0%	<b>1.7%</b>
Agencies Involved in Supporting People with Intellectual Disability	20.0%	12.5%	4.8%	<b>11.7%</b>	33.3%	37.5%	33.3%	<b>35.0%</b>
Management	46.7%	45.8%	57.1%	<b>50.0%</b>	6.7%	0.0%	0.0%	<b>1.7%</b>
<i>Workshop 2</i>								
Challenging behaviour	42.9%	25.0%	66.7%	<b>42.9%</b>	0.0%	0.0%	0.0%	<b>0.0%</b>
Legal and Ethical Considerations	19.0%	8.3%	11.1%	<b>14.3%</b>	23.8%	16.7%	11.1%	<b>19.0%</b>
Lifespan and transition issues	19.0%	25.0%	33.3%	<b>23.8%</b>	9.5%	8.3%	22.2%	<b>11.9%</b>
Personality Disorders, Forensic and D&A issues	33.3%	50.0%	44.4%	<b>40.5%</b>	19.0%	0.0%	11.1%	<b>11.9%</b>
Mental Disorders in other Developmental Disabilities – specific vulnerabilities	14.3%	75%	55.6%	<b>40.5%</b>	9.5%	8.3%	0.0%	<b>7.1%</b>

**Table 10 Ease of Understanding Workshop Material**

	POW	St George	Wollongong	ALL
Workshop 1	<b>mean: 4.50</b> range: (4 – 5) n=14	<b>4.43</b> (3 – 5) n=23	<b>4.84</b> (4 – 5) n=19	<b>4.59</b> (3 – 5) n=56
Workshop 2	<b>4.21</b> (3 – 5) n=19	<b>4.67</b> (3 – 5) n=12	<b>4.11</b> (3 – 5) n=9	<b>4.33</b> (3 – 5) n=40

### *Presenter ratings*

Participants rated presenters very highly on the scale of 1 to 5, with an average rating of 4.4 for Workshop 1, and 4.3 for Workshop 2.

Comments about presenters included:

*"Clear and engaging"*

*"Handled a difficult topic well"*

*"She was interesting and it was good to talk through and work on various group scenarios to consolidate my learning. She gave some great practical tips"*

*"She was very thorough and used humour well, which helped after lunch"*

*"Great to have a consumer present from their point of view, good to see his confidence and sense of humour"*

*"All presenters were very clear in communicating. Good that there were some opportunities for questions."*

*"Easy to understand, confident"*

*"Obviously a communication expert"*

*"Spoke clearly, knew his stuff. Allowed us to think outside the square."*

*"Could speak more clearly."*

*"Clear and concise."*

*"Gave an excellent overview on intake, referral and services."*

Many other comments expressed appreciation for the practical focus taken by presenters, and 14 evaluation forms made positive comments on the use of role plays and other activities.

### *Areas for improvement*

A number of participants commented on aspects of the workshop they found less satisfying, or made suggestions for changes. Two reported feeling the day was too long, and for one workshop two people commented that morning tea was scheduled too late, which we amended in subsequent workshops. One person suggested including information on people from CALD backgrounds, and one wanted certain modules to be more interactive. Some wanted greater depth of information and others felt there was too much information. Six evaluation forms commented they would have preferred fewer interactive activities and role plays.

## **Discussion**

The workshops were well attended by the target group, and evaluation of the workshops was largely very positive. Feedback about individual presentations was incorporated into future presentations wherever possible and reasonable. However some criticisms simply reflect individual differences in learning preferences and needs, and it was clear at the start of the project that some participants' preferences would be better met than others, and that such preferences can be mutually exclusive. This was the case with the activities – with some participants nominating these as a highlight of the workshops, some participants expressing a preference for even more activities, and some participants of the opinion that there were too many.

Thirty-five percent of Workshop 1 participants rated the module *Agencies involved in Supporting People with Intellectual Disability* as the least useful in the workshop. This is of some concern, given half of survey respondents indicated they did not feel confident in referring to ADHC. The reason for nominating this module as the least useful in Workshop 1 is likely to be complex and influenced at least in part by an entrenched “us-versus-them” mentality, which was evident during Workshop 1. A single workshop can assist in redressing this issue, but is unlikely to resolve it alone.

The longer term impact of the workshops on confidence, attitudes and learning needs is currently being assessed. While the workshops are anticipated to have increased confidence and attitudes (as well as knowledge and skills), they proved to be resource intensive to implement and are unlikely to be the most efficient long term solution to the very real learning needs of staff in this area.

This project also represents a number of important developments in efforts to improve the situation for people with ID and mental health needs from multiple angles. Collaboration and cooperation between community agencies and mental health services is pivotal in determining outcomes for people with ID (Mohr et al., 2002). This project, funded by ADHC, hosted by SESIAHS, and implemented by 3DN, represents and strengthens the emerging spirit of partnership and collegiality between NSW Health and ADHC. This collaborative effort was supported at all levels, from the executive level with the approval of the project and awarding of funding, to ground staff attending the workshop (SESIAS) and delivering much of the training (ADHC).

The project has also reinforced 3DN’s position as a key provider, convenor and facilitator of clinical education, expertise, and collaboration in the field of IDMH. The department’s visibility and links to community mental health services, ADHC, and other community support agencies have grown as a result of the project, increasing the potential for 3DN to expand its roles in education, policy, advocacy and research.

## Limitations

The workshops were resource intensive to implement, primarily due to the time taken to develop and prepare for all aspects of such an endeavour. A number of interested staff were unable to attend the workshops due to work commitments, highlighting another weakness inherent in this mode of delivery – there are limited opportunities to engage with the material, and staff may need to travel considerable distances and commit an entire work day to attend.

The workshops intended to deliver a large volume of information over a relatively short period of time, which inevitably left participants with a feeling that they were unable to focus as deeply as they would have liked on certain issues of particular interest. The hope is that this inspired further independent study and learning experiences. However this is undoubtedly another shortcoming of this education format.

## Next steps

Given the significant number of eligible SESIAHS staff who indicated they were unable to attend the workshops despite their interest, one further workshop series will be held at Prince of Wales Hospital in 2011, utilising the resources and relationships established in 2010.

The workshops attracted broad interest beyond the target group from NGOs and other Area Health Services. In the months following the workshops, 3DN received training requests from more than

four other agencies, indicating a strong need for further training and education not only within community mental health teams, but across the sector. Initial calculations reveal that implementing further workshops for other stakeholders is beyond the department's resources at this time, however this may change in the future.

Given the obvious need for further education and training across the industry, 3DN is lobbying for funds to develop an online educational resource based on the workshop materials. Such a resource would have the advantage of being widely and easily accessible, and require far fewer resources to be sustainable in the long term.



## Conclusion

The survey revealed positive attitudes amongst respondents, alongside a strong sense that the current level of training and education in the field of IDMH is lacking.

The workshops were well attended and well received. The workshops were positively evaluated, and they generated interest well beyond the intended target group, raising the profile across the broader health and disability sectors of 3DN and of IDMH, as well as training and education in this field.

Clearly education efforts in this area should continue. However more work and funding is required to formulate a sustainable and far-reaching strategy that delivers maximum value.

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## Appendix 1 Survey

Hardcopy version of survey (6 pages):



### **Intellectual Disability Mental Health - Experience, Confidence and Attitudes**

A joint initiative of UNSW and SESIAHS

Thank you for choosing to complete our survey regarding mental disorders in intellectual disability (ID). You are helping us gather valuable information that will be used to improve training for mental health staff and improve healthcaer for people with intellectual disability.

The survey will take approximately 5 minutes to complete. Please select the best answer for each question.

We have no way of knowing your identity or linking your survey answers to you. However so we can compare surveys if you agree to do it again later, and to make sure there are no duplications, we need you to create a unique code that you'll remember. Please create your unique code using the following steps and fill it in the space below.

1. Select the last two letters of your given name (e.g. Marge select "ge")
2. Select the last two letters of your surname (e.g. Simpson select "on")
3. Select the last three digits of your mobile phone number (e.g. 0444 111 **222** select "222"; if you don't have a mobile phone, select the last three digits of your home phone number)
4. Select "1" if you are female, "2" if you are male
5. Select the first letter of your Network, ie "n" for Northern, "c" for Central and "s" for Southern.

Ignore punctuation in names.

In the above example the code for Marge Simpson who works in the Northern Network would be **geon2221n**

Your unique code: \_ \_ \_ \_ \_

Please select the best answer for each question.

Age	<input type="checkbox"/> Under 20 <input type="checkbox"/> 20 – 29 <input type="checkbox"/> 30 – 39 <input type="checkbox"/> 40 – 49 <input type="checkbox"/> 50 – 59 <input type="checkbox"/> 60 – 69 <input type="checkbox"/> 70 +
Is English your most fluent language?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Highest level of education	<input type="checkbox"/> High school <input type="checkbox"/> TAFE <input type="checkbox"/> University Bachelor Degree <input type="checkbox"/> University Postgraduate Degree <input type="checkbox"/> Other (please specify) _____
How often do you have contact with someone with an intellectual disability in your current professional role?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At least once every month <input type="checkbox"/> At least once every 3 months <input type="checkbox"/> Less than once every 3 months <input type="checkbox"/> I don't recall ever having contact with someone with an intellectual disability in my job
Have you had close personal contact with someone with an intellectual disability (e.g. in your family, socially or as a carer)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you had close professional contact with someone with an intellectual disability (e.g. as a support worker, working for ADHC etc)	<input type="checkbox"/> Yes <input type="checkbox"/> No
To which professional group do you belong?	<input type="checkbox"/> Enrolled Nurse <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Registered Nurse with postgraduate degree <input type="checkbox"/> Other Mental Health Nurse <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Psychologist/Clinical Psychologist/Neuropsychologist <input type="checkbox"/> Social Worker <input type="checkbox"/> Administrative – with direct contact with patients or carers (phone or face to face) <input type="checkbox"/> Administrative – without direct contact with patients or carers <input type="checkbox"/> Other (please specify) _____
Years of experience in your profession	(Please specify) _____
What is your main role in SESIAHS?	<input type="checkbox"/> Clinical <input type="checkbox"/> Managerial <input type="checkbox"/> Education <input type="checkbox"/> Administration <input type="checkbox"/> Other (please specify) _____
Which service/team do you belong to?	<input type="checkbox"/> Acute Care Team <input type="checkbox"/> Case Management <input type="checkbox"/> Consultation Liaison <input type="checkbox"/> Early Intervention <input type="checkbox"/> Acute Inpatient (all admission wards & PEC units) <input type="checkbox"/> Older Person's Mental Health <input type="checkbox"/> Rehabilitation <input type="checkbox"/> Intake <input type="checkbox"/> Other (please specify) _____

Please indicate the extent to which you agree with the following statements (circle one number)

	Disagree strongly	Disagree moderately	Disagree somewhat	Agree somewhat	Agree moderately	Agree strongly
People with intellectual disabilities should not be allowed to marry and have children.	1	2	3	4	5	6
A person would be foolish to marry a person with an intellectual disability.	1	2	3	4	5	6
People with intellectual disabilities can plan meetings and conferences without assistance from others.	1	2	3	4	5	6
People with intellectual disabilities can be trusted to handle money responsibly.	1	2	3	4	5	6
The opinion of a person with an intellectual disability should carry more weight than those of family members and professionals in decisions affecting that person.	1	2	3	4	5	6
Specific workplaces for people with intellectual disabilities are essential.	1	2	3	4	5	6
Increased spending on programs for people with intellectual disabilities is a waste of tax dollars.	1	2	3	4	5	6
Homes and services for people with intellectual disabilities downgrade the neighbourhoods they are in.	1	2	3	4	5	6
People with intellectual disabilities are a burden on society.	1	2	3	4	5	6
Homes and services for people with intellectual disabilities should be kept out of residential neighbourhoods.	1	2	3	4	5	6
People with intellectual disabilities need someone to plan their activities for them.	1	2	3	4	5	6
People with intellectual disabilities do not need to make choices about the things they will do each day.	1	2	3	4	5	6
People with intellectual disabilities can be productive members of society.	1	2	3	4	5	6
People with intellectual disabilities have goals for their lives like other people.	1	2	3	4	5	6
People with intellectual disabilities can have close personal relationships just like everyone else.	1	2	3	4	5	6

	Disagree strongly	Disagree moderately	Disagree somewhat	Agree somewhat	Agree moderately	Agree strongly
People with intellectual disabilities should live in sheltered facilities because of the dangers of life in the community.	1	2	3	4	5	6
People with intellectual disabilities usually should be in group homes or other facilities where they can have the help and support of staff.	1	2	3	4	5	6
Adults with intellectual disability and mental disorders should be treated in mainstream mental health services.	1	2	3	4	5	6
Adults with intellectual disability and mental disorders should have the same access to our service as people without intellectual disability.	1	2	3	4	5	6
Adults with intellectual disability and mental disorders are more difficult for our service to manage.	1	2	3	4	5	6
Most adults with intellectual disability who contact our service have a behavioural problem rather than a mental disorder.	1	2	3	4	5	6
I have had sufficient training regarding mental health and disorders in adults with intellectual disability.	1	2	3	4	5	6
I would be interested in further training in mental health and disorders in adults with intellectual disability.	1	2	3	4	5	6
I can recognise when a patient/client may have an intellectual disability.	1	2	3	4	5	6 *
Mental disorders in adults with intellectual disability can be effectively treated	1	2	3	4	5	6 **
I am confident referring to and liaising with ADHC (Ageing, Disability and Home Care Department).	1	2	3	4	5	6 **

\* Administrative staff with **no direct contact** don't need to answer this question

\*\* No administrative staff need to answer this question



Please note: Administrative Staff with no direct contact do not need to answer any further questions;  
Administrative staff with direct contact need to answer only the first three questions below.

Compared to clients/patients **without** intellectual disability, how confident are you performing the following tasks (circle one number)

	Much less confident for those with intellectual disability	Moderately less confident for those with intellectual disability	Slightly less confident for those with intellectual disability	Equally confident for those with intellectual disability	Slightly more confident for those with intellectual disability	Moderately more confident for those with intellectual disability	Much more confident for those with intellectual disability
Communicate effectively – understanding and being understood.	1	2	3	4	5	6	7
Understand and apply considerations around guardianship and consent.	1	2	3	4	5	6	7
Provide the same general level of service.	1	2	3	4	5	6	7
Understand potential adverse affects of psychotropic medication.	1	2	3	4	5	6	7 *
Identify when further assessment or treatment for a mental disorder is required.	1	2	3	4	5	6	7 *
Identify the risk factors for mental disorders.	1	2	3	4	5	6	7 *
Understand the relationship between behavioural problems and mental disorders.	1	2	3	4	5	6	7 *

\* No administrative staff need to answer these questions

We would value any comments you'd like to add below.

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**Thank you for your time.**

Please fax your completed survey to 9931 9154

OR

Staple the pages together and use the internal mail to post your completed survey to:

Thea Kremser  
Department of Developmental Disability Neuropsychiatry  
34 Botany St  
University of New South Wales NSW 2052

Example of online version of the survey:

Intellectual Disability Mental Health - Experience, Confidence and Attitudes						
Please indicate the extent to which you agree with the following statements						
	Disagree strongly	Disagree moderately	Disagree somewhat	Agree somewhat	Agree moderately	Agree strongly
People with intellectual disabilities should not be allowed to marry and have children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A person would be foolish to marry a person with an intellectual disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with intellectual disabilities can plan meetings and conferences without assistance from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with intellectual disabilities can be trusted to handle money responsibly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The opinion of a person with an intellectual disability should carry more weight than those of family members and professionals in decisions affecting that person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific workplaces for people with intellectual disabilities are essential.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Completed:

## Appendix 2 Learning Objectives Matrix

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>1. Introduction to Intellectual Disability</b> <ul style="list-style-type: none"> <li>Definition of ID</li> <li>Functional effects of ID</li> <li>Causes of ID</li> <li>Associated challenges &amp; vulnerabilities (health, social, psychological)</li> </ul>	Participants will be able to identify when someone may have an ID <ul style="list-style-type: none"> <li>Understand health, social, psychological issues associated with ID</li> <li>Understand the complexity and variety of this disability and its associated syndromes</li> </ul>	How ID presents  Syndromes/conditions often associated with ID  Health, social, psychological issues, situations & challenges associated with ID  Causes of ID	Identify (in a clinical context ) when someone may have an ID
<b>2. Mental Disorders in Intellectual Disability – Introduction</b> <ul style="list-style-type: none"> <li>Similarities and differences to mental disorders in non-ID population               <ul style="list-style-type: none"> <li>Prevalence</li> <li>Triggers</li> <li>Vulnerabilities</li> <li>Presentation</li> <li>Aetiology</li> <li>Monitoring</li> </ul> </li> <li>Other medical comorbidities relevant to mental health</li> </ul>	Participants will be able to identify when someone with an ID may have a mental disorder	How mental disorders can present in someone with ID  How common mental disorders are in people with ID  What can make someone with ID vulnerable to mental disorder  How & why mental disorders arise in someone with ID	Identify when someone with an ID may have a comorbid mental disorder

## MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1

Module & Topics	Learning Objectives	Knowledge	Skills
<b>3. Mental Disorders in Intellectual Disability – Communication and Assessment</b> <ul style="list-style-type: none"> <li>Communication difficulties</li> <li>Assessment <ul style="list-style-type: none"> <li>Similarities and differences compared with non-ID population</li> <li>Assessment tools and guidelines</li> </ul> </li> <li>Enhancing communication and assessment</li> </ul>	Participants will be able to develop effective communication and Ax strategies for clients with ID and comorbid mental disorder <ul style="list-style-type: none"> <li>Consult with carers</li> <li>Involve the clients directly</li> </ul>	Psychiatric assessment tools available for use with clients with ID.  How communication needs of people with ID differ from those of people without ID.  Ways to enhance communication with ID	Engage a person with ID (in a mental health assessment)  Adapt communication to facilitate exchange of information with someone with ID and mental disorder.  Appropriately gather relevant information regarding from carers and from a person with ID.
<b>4. Agencies Involved in Supporting People with Intellectual Disability</b> <ul style="list-style-type: none"> <li>Agencies</li> <li>Care pathway for clients with ID and comorbid mental disorder</li> </ul>	Participants will be able to appropriately refer to and work with ADHC and other associated agencies in ensuring best possible care <ul style="list-style-type: none"> <li>Understand the scope of ADHC, other associated agencies, and Community Mental Health Services in responding to the needs to clients with an intellectual disability and comorbid mental disorder</li> </ul>	CMH role in supporting people with IDMH issues.  ADHC's services and to whom they're available.  Other agencies involved in supporting people with IDMH issues.  Care pathways.	Refer to and collaborate with other agencies.

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>5. Mental Disorders in Intellectual Disability – Management</b> <ul style="list-style-type: none"> <li>• Introduction – context</li> <li>• Medication <ul style="list-style-type: none"> <li>◦ Similarities and differences compared with non-ID population</li> </ul> </li> <li>• Psychosocial interventions <ul style="list-style-type: none"> <li>◦ Similarities and differences compared with non-ID population</li> </ul> </li> <li>• Ideal interventions (complex, support from multiple angles)</li> </ul>	Participants will be able to develop effective management strategies for clients with ID and comorbid mental disorder <ul style="list-style-type: none"> <li>• Understand use of Rx and psychosocial interventions in clients with ID and comorbid mental disorder</li> </ul>	Use of Rx in clients with IDMH.  Use of psychosocial interventions in clients with IDMH.  Ideal management of IDMH.	Develop management strategies for clients with IDMH (referring to psychiatrist for Rx, referring appropriately for psychosocial Ax/intervention, referring appropriately to other social agencies).
MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>6. Mental Disorders in Intellectual Disability – Challenging Behaviour</b> <ul style="list-style-type: none"> <li>• What is challenging behaviour</li> <li>• Relationship between challenging behaviour and mental health</li> <li>• Challenging behaviour in clients with ID and comorbid mental disorder</li> <li>• Approaches to assessment and management of challenging behaviour in clients with ID and comorbid mental disorder</li> </ul>	Participants will be able to understand challenging behaviour and its relationship to mental disorder in people with an intellectual disability <ul style="list-style-type: none"> <li>• Understand assessment and management of challenging behaviour related to a mental disorder</li> </ul>	What is challenging behaviour?  How challenging behaviour develops  Relationship of challenging behaviour to mental disorders in people with ID  Agencies/roles involved in assisting with/managing challenging behaviour	Investigate possible mental health issues underlying challenging behaviour.  Collaborate with other agencies in investigating and managing challenging behaviour.

## MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1

Module & Topics	Learning Objectives	Knowledge	Skills
<b>7. Mental Disorders in Intellectual Disability – Legal and Ethical Considerations</b> <ul style="list-style-type: none"> <li>Duty of Care</li> <li>Mental Health Act 2007</li> <li>Decision Making <ul style="list-style-type: none"> <li>The Guardianship Act 1987</li> <li>The Powers of Attorney Act 2003</li> <li>Consent</li> <li>Assessing capacity to give consent</li> <li>Supporting the person who cannot give consent – similarities and differences to non-ID population</li> </ul> </li> </ul>	Participants understand and incorporate relevant ethical and legal considerations when working with clients with ID and comorbid mental disorder	<p>The service's and the mental health professional's duty of care to a client with IDMH – differences compared with non-ID</p> <p>How the MH Act 2007 relates to clients with IDMH</p> <p>The decision making process involving clients with IDMH</p> <p>What is and is not consent</p> <p>How decisions are made on behalf of those who lack the capacity to give consent</p> <p>The role of the support worker and other professionals in consent</p>	<p>Assessing capacity to give consent</p> <p>Supporting the person with IDMH who cannot give consent</p>
<b>8. Mental Disorders in Intellectual Disability – Lifespan and Transition Issues</b> <ul style="list-style-type: none"> <li>Children &amp; young people with ID <ul style="list-style-type: none"> <li>Vulnerabilities to mental disorder</li> <li>Presentation of mental disorder</li> <li>Family and social issues</li> </ul> </li> <li>Older people with ID <ul style="list-style-type: none"> <li>Vulnerabilities compared with non-ID population</li> <li>Dementia and other mental disorders</li> </ul> </li> </ul>	Participants will develop an understanding of lifespan and transition issues in clients with ID and comorbid mental disorder	<p>Issues associated with transitions between life-stages; key vulnerabilities to mental disorders associated with same</p> <p>Mental disorders &amp; dementia in older people with ID</p> <p>Mental disorders in younger people with ID</p> <p>Mental disorders in children with ID</p>	<p>Identify vulnerabilities to mental disorder in people with ID going through certain life changes.</p> <p>Identify vulnerabilities to mental disorder in people with ID in certain age-groups</p>

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>9. Mental Disorders in Intellectual Disability – Personality Disorders, Forensic, and D&amp;A Issues</b> <ul style="list-style-type: none"> <li>• Personality disorders in intellectual disability</li> <li>• Offending behaviour in intellectual disability</li> <li>• D&amp;A issues in intellectual disability</li> </ul>	Participants will develop an understanding of personality disorders, forensic and D&A issues associated with ID and comorbid mental disorder	Offending and D&A use in people with ID and mental disorders – differences compared with non-ID.  Personality disorders in people with ID – differences compared with non-ID  Relationship between mental disorder and offending and D&A use in ID population.	
<b>10. Mental Disorders in Other Developmental Disabilities – Specific Vulnerabilities</b> <ul style="list-style-type: none"> <li>• Autism Spectrum Disorders               <ul style="list-style-type: none"> <li>○ Definition, description, functional effects, causes</li> <li>○ Vulnerability to MH issues</li> <li>○ Presentation of MH issues</li> <li>○ Enhancing communication</li> </ul> </li> <li>• Down Syndrome and other important behavioural phenotypes with MH vulnerabilities.</li> </ul>	Participants will be able to understand the presentation and management of mental disorders in people with other developmental disabilities	Presentation of ASDs  Mental disorders in ASD – presentation and management  Strategies to improve communication  Vulnerability to dementia in Down Syndrome	Adapt communication to facilitate exchange of information with people with ASD  Investigate presence of mental disorder in people with ASD  Identify vulnerabilities to mental disorder in ASD

## Appendix 3 Information Frameworks for Modules 1-10

### MODULE 1

#### Introduction to Intellectual Disability

#### Information framework for presenters

WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>1. Introduction to Intellectual Disability</b> <ul style="list-style-type: none"><li>• Definition of ID</li><li>• Functional effects of ID</li><li>• Causes of ID</li><li>• Associated challenges &amp; vulnerabilities (health, social, psychological)</li></ul>	Participants will be able to identify when someone may have an ID <ul style="list-style-type: none"><li>• Understand health, social, psychological issues associated with ID</li><li>• Understand the complexity and variety of this disability and its associated syndromes</li></ul>	How ID presents  Syndromes/conditions often associated with ID  Health, social, psychological issues, situations & challenges associated with ID  Causes of ID	Identify (in a clinical context ) when someone may have an ID

*This module aims to give a general introduction to intellectual disability. The information in this module will provide a context for the rest of the workshop, which focuses specifically on mental disorders in intellectual disability.*

#### Definition of intellectual disability

For example DSM-IV-TR, World Health Organisation (WHO) ICD-10, and/or American Association on Intellectual and Developmental Disabilities (AAIDD) definitions.

#### Definition of developmental disability

Including the distinction and the connection between DD and ID.

#### Prevalence of intellectual disability

Note difficulties in obtaining a population estimate; prevalence estimates vary from 0.4% - 3.0% (AIHW, 2003 <http://www.aihw.gov.au/publications/index.cfm/title/9671>).

#### Effects of intellectual disability on the individual

Explain that intellectual disability can have a variety of complex effects on a person. Intellectual disability is associated with deficits in adaptive functioning that might include:

- Conceptual skills — language and literacy; money, time, and number concepts; and self-direction.
- Social skills — interpersonal skills, social responsibility, self-esteem, naïveté (i.e., wariness), problem solving, and the ability to follow rules/obey laws and to avoid being victimised.



- Practical skills — activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

### Causes of ID

- Genetic factors/syndromes (eg Fragile X Syndrome; Down Syndrome)
- Social ecological factors (e.g. infection before, during or after birth; oxygen deprivation during labour; early health problems or poor health care; extreme premature birth, drug/alcohol misuse during pregnancy)
- AAIDD – ‘Approximately 40 to 50 percent of the causes of intellectual disabilities currently have no identifiable origin’

### Indicators of ID<sup>1</sup>

Intellectual disability can affect people in diverse ways and has diverse causes, and the severity of the disability varies widely. It is not always easy to recognise when someone might have an intellectual disability. Sometimes the disability may be caused by a syndrome that has associated physical characteristics, such as Down Syndrome, but this is not always the case.

Possible indicators of Intellectual Disability <sup>1</sup>		
Activities	Remember	Life Experiences
Can they: <ul style="list-style-type: none"> <li>• read</li> <li>• write</li> <li>• manage money</li> <li>• look after their personal care</li> <li>• tell the time</li> <li>• cook</li> <li>• do they have difficulty in communicating with other people?</li> </ul>	Can they remember: <ul style="list-style-type: none"> <li>• significant things about themselves (e.g. birthday)</li> <li>• significant things about their environment (e.g. where they live)</li> <li>• when to do things (get up, what time dinner is)</li> <li>• what you have said?</li> </ul>	Have/do they: <ul style="list-style-type: none"> <li>• attend a special school or class within a mainstream school</li> <li>• attend a day centre</li> <li>• live(d) in an institution or intellectual disability service</li> <li>• have people who support them (e.g. care worker, advocate etc)</li> <li>• manage in social situations?</li> </ul>

It is important to take into account other factors that may explain possible signs of ID, such as cultural factors.

### Larger impact of ID on the service user

Adults with ID experience disadvantage, reduced opportunities, and other barriers to health and wellbeing in multiple areas of health, social, interpersonal, and personal functioning as outlined below.

#### Health care

Life expectancy is significantly lower than for the general population, and is dependent on severity of ID – ranges from approximately 10 years to 20 years lower than the general population for those with severe ID (Bittles et al. 2002)

Specific health challenges include significantly increased incidence of:

<sup>1</sup> Intellectual Disability Mental Health First Aid Manual (2009), Adapted by Ruth Pappas and Matt Frize, Office of the Senior Practitioner (OSP), NSW Department of Ageing Disability and Homecare (DADHC).

- Dental disease (up to seven times higher incidence, and poor rate of treatment; Scott et al. 1998)
- Vision impairment and eye disorders (seven to 20 times higher incidence, and poor rate of treatment; Beange, McElduff & Baker, 1995)
- Hearing Impairment
- Thyroid problems
- Epilepsy
- Lifestyle-related health problems
  - Overweight and obesity
  - Constipation
  - Poorer levels of physical fitness
  - Polypharmacy
- Gastroesophageal reflux disease (GERD)
- Multiple chronic complex disorders
- Hospitalisation (twice as likely as general population)
- Serious injury (twice as likely as general population)

People with ID tend to be less likely to complain, exacerbating these health challenges. Because they are often reliant on third party report, a large proportion of health problems go undetected and untreated in adults with ID.

### *Life experiences*

Adults with ID often experience limitations in their participation of many social and community experiences:

- Employment/vocational pursuits
- Accommodation
- Community participation
- Choice making/independence
- Interpersonal relationships and social inclusion
- Stigma and stereotyping

This often has a negative impact on their sense of self esteem and confidence, and limits the sources of enjoyment and satisfaction available to adults with ID. Clearly this can have a significant impact on the quality of life of adults with ID.

### *Mental Health*

Adults with ID are at increased risk of developing mental health problems, and this is likely to reflect a complex interaction of the factors listed above, and other factors that will be covered in the next module, and be the focus of remaining modules.

On the other hand, it can be difficult in some situations to distinguish between decompensation due to mental illness (such as negative symptoms of schizophrenia) and ID. Discuss the importance of taking a thorough history, including a functional history and a developmental history (the onset of most mental illness is after the age of 18/in late teens, while intellectual disability is usually present much earlier).

## Mental Disorders in Intellectual Disability – Introduction

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>2. Mental Disorders in Intellectual Disability – Introduction</b> <ul style="list-style-type: none"> <li>Similarities and differences to mental disorders in non-ID population               <ul style="list-style-type: none"> <li>Prevalence</li> <li>Triggers</li> <li>Vulnerabilities</li> <li>Presentation</li> <li>Aetiology</li> <li>Monitoring</li> </ul> </li> <li>Other medical comorbidities relevant to mental health</li> </ul>	Participants will be able to identify when someone with an ID may have a mental disorder	How mental disorders can present in someone with ID  How common mental disorders are in people with ID  What can make someone with ID vulnerable to mental disorder  How & why mental disorders arise in someone with ID	Identify when someone with an ID may have a comorbid mental disorder

*This module aims to give a broad introduction to mental disorders in intellectual disability to the target audience of mental health workers who have a basic understanding of intellectual disability concepts, causes, and prevalence.*

Most with an ID have only a mild level of disability, and resemble the normal population in presentation, vulnerability factors, and treatment needs for mental illness and mental health problems. Emphasise that participants already have the skills template on which to build more specialised skills for this population.

**Prevalence of mental disorders – general population and ID population compared***General population*

- Approx. 45% of the general population will experience a mental disorder at some time in their life (2007 National Survey of Mental Health and Wellbeing)
- 20% of the general population experienced a mental disorder within the past 12 months (2007 National Survey of Mental Health and Wellbeing)
- Of this 20%, anxiety disorders were most common (14.6%); followed by affective disorders (6.2%) and substance use disorder (5.1%)

*ID population*

People with ID can experience the full range of mental disorders found in people without ID.

- Prevalence rates vary depending on the diagnostic criteria used, instruments used for detection of mental disorders, the population sampled (e.g. children v. adults; institutional vs community); and whether 'behavioural disorder' was included

- Prevalence estimates vary due to differing definitions and methodologies, and estimates vary from 7% to 97% (Cooper et al 2007). An Australian survey of people with ID found 1.3% had a psychotic disorder, 8% had a depressive disorder and 14% had an anxiety disorder that had been present for at least 6 months and was of high severity (White, Chant, Edwards, Townsend, & Waghorn, 2005). See also Costello & Bouras (2006) and Whitaker & Read (2006).
- People with ID are less likely to be receiving treatment for their mental disorder and are often unknown to mental health services (Eaton & Menolascino 1982; Moss *et al.* 1996). Reasons for this include (from Emerson & Holland, 1997):
  - families and care staff untrained in mental health disorders and unable to recognise potential indicators,
  - lack of appropriately trained health professionals;
  - diagnostic difficulties such as diagnostic and behavioural overshadowing
  - until very recently there has been little research on the use of psychological therapies in people with ID other than behavioural treatments

### Presentation

Common presentation of major mental disorders compared – Psychiatric disorders in adults with mild ID and/or reasonable verbal communication skills have presentations similar to those in adults without ID. Psychiatric disorders in adults with severe ID, those with ID and autism and/or those with limited verbal communication skills are more likely to present with changes to their behaviour, including disturbed or regressed behaviour.

The next module will delve deeper into communication and assessment, but in this module briefly outline features of the presentation of mental disorders in adults with ID that can make the diagnosis and recognition of a mental disorder difficult (and which underpin the need for a special focus on communication and assessment):

- diagnostic overshadowing (a symptom of a mental disorder e.g. incontinence is incorrectly attributed to the ID, or a symptom of the ID (such as disorganised speech) is incorrectly attributed to a mental disorder (such as psychosis))
- intellectual distortion i.e. *‘Concrete thinking and impaired communication result in poor communication about their own experience’* e.g. *‘Client describes self as ‘scared’ instead of ‘mad’ because of poor verbal skills’* (Sturmey, 2007, p. 10)
- psychosocial masking i.e. *‘Impoverished social skills and life experiences result in unsophisticated presentation of a disorder or misdiagnosis of unusual behaviour as a psychiatric disorder’* e.g. *‘Giggling and silliness is misdiagnosed as psychosis’* (Sturmey, 2007, p. 10)
- baseline exaggeration i.e. *‘Prior to the onset of a disorder there are high levels of unusual behaviours, making it difficult to recognize the onset of a new disorder’* e.g. *‘A person who already had poor social skills and was withdrawn becomes more so and begins to experience other signs and symptoms of depression. This is missed because staff reports are inaccurate and staff turn-over means that no-one is aware of the overall change in the person’s functioning’.* (Sturmey, 2007, p.10)
- cognitive disintegration i.e. *‘Bizarre behaviour is presented in response to minor stressors that could be misdiagnosed as a psychiatric disorder’* e.g. *‘A client is highly disruptive and*

Sturmey, P. (2007) Diagnosis of mental disorders in people with intellectual disabilities. In Bouras, N., & Holt, G. (Eds.), *Psychiatric and behavioural disorders in intellectual and developmental disabilities*. (2<sup>nd</sup> ed., pp. 3-23) Cambridge, UK: Cambridge University Press.

- The possibility of underlying physical illness/disorder (such as pain, earache or constipation) accounting for the recent onset of disturbed behaviour should be considered in adults with learning disabilities unable or unwilling to complain verbally.

#### *Mood disorders*

- Depressive disorders: similarities and differences in presentation
- Bipolar disorders: similarities and differences
- Anxiety disorders: similarities and differences

#### *Psychotic disorders*

- Schizophrenia: similarities and differences

#### *Medical disorders*

- Dementia – increased risk of early dementia associated with Down Syndrome
- Delirium – increased risk with ID

### **Vulnerabilities**

Examine factors that contribute to the increased vulnerability of adults with ID to mental health problems, drawing the link to increased prevalence and conversely drawing out factors that are protective.

#### *Vulnerabilities:*

##### **Biological**

- Brain damage/epilepsy
- Vision/hearing impairments
- Physical illnesses/disabilities – higher incidence and lower rate of detection and treatment
- Genetic/familial conditions (autism, behavioural phenotypes etc)
- Drugs/alcohol abuse
- Medication/physical treatments

##### **Psychological**

- Rejection/deprivation/abuse
- Life events/separations/losses
- Poor problem-solving/coping strategies
- Social/emotional/sexual vulnerabilities
- Poor self-acceptance/low self-esteem
- Devaluation/disempowerment

##### **Family**

- Diagnostic/bereavement issues
- Life-cycle transitions/crises
- Stress/adaptation to disabilities
- Limited social/community networks
- Attachment difficulties

##### **Social**

- Negative attitudes/expectations
- Stigmatisation/prejudice/social exclusion
- Poor supports/relationships/networks

- Inappropriate environments/services
- Financial/legal disadvantages

### **Triggers and Aetiology**

Triggers = more immediate, situational vulnerabilities to developing a mental disorder. Discuss factors that differ in the aetiology of mental disorders in people with ID compared to those without ID.

- Risk factors that increase the development of mental health problems cluster in the lives of adults with an ID, for example genetic, biochemical, negative early experiences, psychosocial stressors and cognitive/ behavioural problems (Emerson, 1996)
- People with an ID are more likely to experience poor general health, and are more likely to be exposed to poverty during childhood (Emerson & Hatton, 2008)
- Children with ID are more likely to be exposed to all forms of social disadvantage (e.g. lone-parent family; poverty; exposure to two or more negative life events; poor family functioning; primary carer with no educational qualifications; household with no paid employment; mother with potential mental health disorder; poor maternal physical health), and social disadvantage is associated with psychopathology (Emerson & Hatton, 2007).
- Negative impact of ID on families (risk of increased stress/maladjustment) is more likely to lead to out-of-home placements (Emerson & Hatton, 2007).
- Socio-economic disadvantage and household position accounted for 37% of the increased risk in developing emotional disorders in children with ID (Emerson & Hatton, 2008) (Note: there is also an established link between social disadvantage and ID (Schoon et al. 2005; Emerson et al, 2006b))
- People with ID are likely to experience more negative social support ("social strain") compared to the general population as they often do not have the same level of freedom to choose who they spend time with to maximise positive social interactions and minimise negative social interaction (e.g. group home situation, reduced employment opportunities) – the presence of social strain is associated with psychopathology (Lunsky & Havercamp, 1999)

### **Prevention**

- Increased opportunity for choice and independence
- Skill building and promotion of resilience – teach coping strategies, problem solving, relaxation strategies, communication skills, develop support system e.g. who to talk to about problems/issues
- Increased activity - reduce boredom and increase opportunities to feel a sense of achievement and purpose via day programs, social groups, sports or hobbies, community college courses, etc
- Environmental modifications – e.g. family/staff training in mental health, early warning signs, how to provide a supportive, validating environment, changes to light/noise/space

### **Epilepsy**

## Mental Disorders in Intellectual Disability – Communication and Assessment

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>3. Mental Disorders in Intellectual Disability – Communication and Assessment</b> <ul style="list-style-type: none"> <li>Communication difficulties</li> <li>Assessment <ul style="list-style-type: none"> <li>Similarities and differences compared with non-ID population</li> <li>Assessment tools and guidelines</li> </ul> </li> <li>Enhancing communication and assessment</li> </ul>	Participants will be able to develop effective communication and Ax strategies for clients with ID and comorbid mental disorder <ul style="list-style-type: none"> <li>Consult with carers</li> <li>Involve the clients directly</li> </ul>	Psychiatric assessment tools available for use with clients with ID.  How communication needs of people with ID differ from those of people without ID.  Ways to enhance communication with ID	Engage a person with ID (in a mental health assessment)  Adapt communication to facilitate exchange of information with someone with ID and mental disorder.  Appropriately gather relevant information regarding from carers and from a person with ID.

*This module covers specific issues relating to communication and assessment of mental disorders for adults with ID. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

Emphasise that most with an intellectual disability have a mild intellectual disability and resemble the normal population in how they present with mental illness and in their communication needs and in the general approach to assessment. Emphasise that participants already have the communication and assessment skills on which to build more specialised skills for this population.

**Communication***The affect of ID on communication*

Highlight the ways in which a service user's ability to communicate might be affected by intellectual disability, and explain that these vary significantly according to level of ID. Note that those with mild ID will be able to engage in communication in a similar way to those without ID, while the communication skills of those with more severe ID will be profoundly affected. Give examples of the aspects of ID that affect communication eg concrete thinking, difficulties understanding abstract concepts such as emotions, difficulties understanding of social cues, low confidence, suggestibility, physical speech impairments etc.

### *Principles*

Respect: Establishing a sense of mutual respect is important for the success of any communication, however due to the stigma and social discrimination that are often associated with intellectual disability it is especially important in this context. Ways to foster a feeling of respect and esteem include

- Speaking directly with the person
- Reflecting what the person has said
- Making eye contact and being open/friendly
- Appropriately modifying aspects of language and speech to match the person's level of ability
- Checking the person's understanding

Because ID is complex and affects individuals differently, it is more important to approach communication in a flexible and adaptable way, rather than applying the same modifications and strategies to every person with ID.

Be strategic: Remind participants that communication has certain functions and goals which basically involve obtaining and providing information. A situation involving communication impairments may require some alternative or additional strategies to those we take for granted in regular communication. The approach will depend on the situation, and may include consulting with carers and family and other adjustments such as those included below.

### *Methods*

Discuss different methods of communication, structuring these according to level of ID (mild, moderate, severe, profound) e.g.

- Vocalisations (sounds, single words, phrases, sentences), writing, eye gaze, facial expressions, reaching/touching/tapping, pointing to people objects/areas, leading people or pulling people towards something, manually guiding someone, handing/pushing objects toward someone to request something, showing an object or picture, standing/sitting near item, demonstrating an action, common gestures (e.g. wave, head nod), made-up gestures and signals, socially undesirable behaviour or "challenging behaviour" (e.g. throwing objects)
- Augmentative and alternative communication (AAC), language modification (e.g. shorter sentences, use key words, longer pauses, no abstract concepts, no jargon, use gestures, one-step instructions, ask open rather than closed questions due to a greater tendency to acquiesce etc)
- Communication books (look in patient's bag) and asking multidisciplinary team how they communicate with person
- The use of an interpreter may be appropriate – either a formal interpreter or family/carers who are familiar with idiosyncratic communication
- The importance of consulting with carers and/or family, both to obtain information and to provide feedback and coordinate care



## Assessment

Assessment for mental disorders in people with an ID – address adaptations for interviewing and assessing the service user. Discuss the importance of consulting with carers and supports (professional and/or family) to elaborate, give time-frames of signs and symptoms etc. Discuss the importance of including the service user in the process of consulting with carers and supports, and of maintaining service user's dignity through the process. Discuss the importance of providing feedback to both the individual and to carers, in order to support the implementation of care.

Compare the ICD-10 and the DSM IV criteria that have been adapted for people with ID with the original criteria. Note that there exist mental health assessment tools designed for people with an ID – e.g. *Diagnostic Manual – Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Psychiatric Assessment Schedule for Adults with Developmental Disability Checklist (PAS-ADD), Developmental Behaviour Checklist for Adults (DBC-A), Dementia Questionnaire for Persons with Mental Retardation (DMR), DBC Autism Screening Algorithm (DBC-ASA), Dementia Scale for Down Syndrome.

## Agencies Involved in Supporting People with Intellectual Disability

**Information framework for presenters**

<b>MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1</b>			
<b>Module &amp; Topics</b>	<b>Learning Objectives</b>	<b>Knowledge</b>	<b>Skills</b>
<b>4. Agencies Involved in Supporting People with Intellectual Disability</b> <ul style="list-style-type: none"> <li>Agencies</li> <li>Care pathway for clients with ID and comorbid mental disorder</li> </ul>	Participants will be able to appropriately refer to and work with ADHC and other associated agencies in ensuring best possible care <ul style="list-style-type: none"> <li>Understand the scope of ADHC, other associated agencies, and Community Mental Health Services in responding to the needs to clients with an intellectual disability and comorbid mental disorder</li> </ul>	CMH role in supporting people with IDMH issues.  ADHC's services and to whom they're available.  Other agencies involved in supporting people with IDMH issues.  Care pathways.	Appropriately refer to and collaborate with other agencies.

*This module provides an introduction to the different agencies that provide support to adults with an intellectual disability who may have a mental health problem, and to referral pathways. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

**Services for People with an Intellectual Disability**

Outline the different types of services available to adults with ID, how they're coordinated and accessed. Refer to those that offer:

- Accommodation e.g. private rental, NSW Housing, ADHC (and ADHC-funded organisations), non-government organisations
- Drop in Support
- Respite
- Occupational/Vocational Services – post school options, adult day programs, supported employment, employment agencies
- Behaviour Support – ADHC, ADHC-funded organisations, private consultants
- Case Coordination
- Counselling
- Health and Medical e.g. private psychiatrists/psychologists, GPs
- Guardianship

## **ADHC**

Explain the role of ADHC and the services ADHC provides to adults with ID and mental health needs.

### *ADHC Direct Services*

- 'Metro South' and 'Southern' geographical areas, and Information Referral and Intake (IRI) contact details and referral process
- Eligibility criteria
- Brief detail of services available
- 'Stronger Together' programs

### *ADHC-funded and Non-Government Organisations*

- Intake process and eligibility criteria
- Services available e.g. day programs, accommodation, clinical services

### *Other available services (partially funded by departments such as ADHC/FACSIA/NSW Health and other sources)*

- Family Planning NSW has a lot of resources on sexual health and sexuality for pwID
- Intellectual Disability Rights Service – have lawyers who work exclusively with pwID
- Abuse and Neglect hotline – to report suspected or actual instances of abuse or neglect
- Individual Advocacy Services – MDAA, PWD, if a patient may need a stronger voice, but not at the guardianship level

## **Diagnostic and Assessment Services**

- Intake process and eligibility criteria

## **Possible/optional case examples**

Case Example 1 – service user presenting to mental health services who has an ID and is not yet linked in with disability services – where to refer and what is available. Highlight collaborative service provision.

Case Example 2 – service user who is already linked in with disability services, develops a mental illness and requires mental health support

or

Process of a family member of someone with a disability obtaining mental health support for the person

## Mental Disorders in Intellectual Disability – Management

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 1			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>5. Mental Disorders in Intellectual Disability – Management</b> <ul style="list-style-type: none"> <li>• Introduction – context</li> <li>• Medication <ul style="list-style-type: none"> <li>◦ Similarities and differences compared with non-ID population</li> </ul> </li> <li>• Psychosocial interventions <ul style="list-style-type: none"> <li>◦ Similarities and differences compared with non-ID population</li> </ul> </li> <li>• Ideal interventions (complex, support from multiple angles)</li> </ul>	Participants will be able to develop effective management strategies for clients with ID and comorbid mental disorder <ul style="list-style-type: none"> <li>• Understand use of Rx and psychosocial interventions in clients with ID and comorbid mental disorder</li> </ul>	Use of Rx in clients with IDMH. <ul style="list-style-type: none"> <li>• Rationale</li> <li>• Best practice</li> <li>• Common errors/mistakes in prescribing for adults with ID</li> </ul> Use of psychosocial interventions in clients with IDMH. <p>Ideal management of IDMH.</p>	Develop management strategies for clients with IDMH (referring to psychiatrist for Rx, referring appropriately for psychosocial Ax/intervention, referring appropriately to other social agencies).

*This module introduces the management of mental disorders in adults with Intellectual Disability. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

Remind participants that most with an intellectual disability have a mild intellectual disability and resemble the normal population in how they present with mental illness and in the appropriate treatment for mental health problems. Emphasise that participants already have the skills template on which to build more specialised skills for this population.

**Medication***Similarities and differences compared with non-ID population*

The principles of prescribing (dependent on diagnosis, symptoms, duration and severity, risk, side effect profile, previous responses to Rx, response to Rx) for people with intellectual disability are the same as for people without intellectual disability. Generally medication should form a component of treatment, rather than being a stand-alone treatment.

However prescribing medication for an adult with an intellectual disability can present a more complex scenario than for adults without intellectual disability. Considerations that contribute to this include:

- Additional difficulty in ensuring an accurate diagnosis – if the diagnosis used to guide prescribing is incorrect, the medication is less likely to work
- Compliance
- Medical complications e.g. swallowing difficulties, epilepsy, reflux, constipation etc.

- Consent issues
- The importance of actively monitoring side effects – a symptom may be a side effect, or may be due to an underlying illness
  - Consider how someone with ID may communicate side effects, particularly in the context of communication difficulties
  - Explain how to best monitor side effects in someone with ID, and how to involve carers/supports in monitoring and assessing side effects.
- Many with intellectual disability are significantly more sensitive to psychotropic medication than those without ID. Side effects in adults with ID may be more frequent, more intense, and more idiosyncratic
- Assessing efficacy
- Difficulties arising in the care setting
  - Carer knowledge or training
  - Medication used as substitute for substitute for psychosocial intervention
  - Biases of staff and carers involved in decision-making – both inappropriate calls for sedative medication and resistance to appropriate use of medication for mental illness
- Poor evidence for the use of psychotropic Rx in adults with ID (due to heterogeneity of this group and inability to consent to participation in clinical trials)

*Common errors in the use of psychotropic medication in adults with ID include:*

- Overdosing, leading to sedation
- Under- and over-prescribing
- Extended use of crisis medications
- Use as a substitute for non-medical therapies
- Medications used to suppress “reasonable” emotions/behaviour, such as grief
- Medications continued despite no change in signs/symptoms
- Carers’ and clinicians’ response to toxicities/side effects may be delayed due to poor self-advocacy
- Polypharmacy
- Use of “older” versions of medication that have more side effects
- No review mechanisms
- Lack of clarity and consensus in prescribing practices
- Antipsychotics are the most common class of medication prescribed to adults with ID, however often with no rationale for use

*Principles for optimal prescribing:*

- Biopsychosocial assessment
- Monitor physical health
- Start at lower doses
- Educate about adverse reactions and side effects
- Routine ongoing review
- If treatment is ineffective, reconsider diagnosis
- Multidisciplinary decision making
- Collaborate with consumers and carers
- Use medication as an adjunct to other interventions

*Medication and challenging behaviour:*

- Indicated for severe challenging behaviour where psychosocial interventions have failed
- Three possible ways that Rx may help in this case:
  1. non-specific reduction in agitation and over-arousal
  2. specifically targeting the neurochemical mechanisms responsible for the challenging behaviour
  3. may treat an underlying mental illness that has contributed to the challenging behaviour
- Most common types of medication used:
  - Antipsychotics
  - Antidepressants
  - Mood stabilizers

- Indicated for behaviours such as:
  - Self-injurious behaviour
  - Aggression
  - Ritualistic behaviours
  - Stereotypies

### **Treatment Planning**

Overall treatment planning usually involves a number of strategies, delivered by one or more services, that might include:

- Psychoeducation for staff/family
- Psychoeducation for service user – e.g. in social story format
- Implementation and analysis of mood monitoring or other data collection (e.g. sleep charts)
- Development of a 'mental health support plan' or similar, tailored to the individual that includes typical signs/symptoms of the person's mental health diagnosis, early warning signs, steps to take when early warning signs emerge, steps to take to manage a crisis – what to do, who to call and when to call them
- Development of a 'Behaviour Support plan' for managing challenging behaviour (mental health support plan be incorporated into it)
- Possibility of additional respite to reduce the stress on families (for home-based clients)
- Possibility of increased support staff or changes to staffing roster (for group home clients)
- Referral to mental health – for one or more of the following services:
  - a) Initial assessment /diagnosis
  - b) Monitoring of mental health symptoms
  - c) Establishment or ongoing review of medication
  - d) Direct psychological treatment or assistance with same
  - e) Psychoeducation or assistance with provision of psychoeducation
  - f) Assistance in development and review of overall treatment plan
  - g) Assistance with development of mental health support plan
  - h) Acute care services
  - i) Inpatient services
- Referral to private psychologist/counsellor for intervention – e.g. CBT, DBT, graded exposure, etc.
- Development of new interaction guidelines – information for family and/or support staff to guide them in how to interact with the person, taking into account their mental health diagnosis
- Changes to weekly routine – e.g. reduction in attendance at job or day program, or alterations to hours/tasks performed

### **Direct Treatment**

Psychosocial interventions, including CBT, relaxation training and other therapies, can be used with some adults with intellectual disability. However adults with intellectual disability are likely to require extra support, such as: engagement of other supports involved to help with practicalities, or in some cases with the "homework" from CBT; or for information about the triggers, presentation etc for certain aspects of the disorder;

Models of therapy have to be adapted for use with people with ID:

- use of simple language
- use of concrete terms rather than theoretical ideas
- willingness to work in the long term
- reduced reliance on homework and the written word
- increased use of symbols
- increased use of pictures
- increased emphasis on behavioural interventions and recordings
- flexible approach to length of sessions
- flexible approach to location of therapy
- greater involvement of significant others.

Ideal interventions are complex, and involve support from multiple angles.

**Behavioural Approaches**

- Research demonstrating efficacy and with what specific population/presenting problem
- Practical examples

**CBT**

- Research demonstrating efficacy and with what specific population/presenting problem
- Practical examples

**DBT**

- Research demonstrating efficacy and with what specific population/presenting problem
- Practical examples

**Psychodynamic Psychotherapy**

- Research demonstrating efficacy and with what specific population/presenting problem
- Practical examples

## Mental Disorders in Intellectual Disability – Challenging Behaviour

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>6. Mental Disorders in Intellectual Disability – Challenging Behaviour</b> <ul style="list-style-type: none"> <li>What is challenging behaviour</li> <li>Relationship between challenging behaviour and mental health</li> <li>Challenging behaviour in clients with ID and comorbid mental disorder</li> <li>Approaches to assessment and management of challenging behaviour in clients with ID and comorbid mental disorder</li> </ul>	Participants will be able to understand challenging behaviour and its relationship to mental disorder in people with an intellectual disability <ul style="list-style-type: none"> <li>Understand assessment and management of challenging behaviour related to a mental disorder</li> </ul>	What is challenging behaviour?  How challenging behaviour develops  Relationship of challenging behaviour to mental disorders in people with ID  Agencies/roles involved in assisting with/managing challenging behaviour	Investigate possible mental health issues underlying challenging behaviour.  Collaborate with other agencies in investigating and managing challenging behaviour.

*This module covers Challenging Behaviour in adults with ID, and the relation to mental health problems. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

**Section 1: Clinical****Challenging behaviour – definition**

*“...behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.”*  
(Emerson 1995)

Newer definition:



Challenging behaviour may be defined as:

*“Behaviour...of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.”* (Banks et al, 2007)

**Intensity** – the strength of the behaviour, eg how hard someone hits another

**Frequency** – how often the behaviour occurs

**Duration** – how long the behaviour lasts. These parameters are used to determine the effects of the behaviour – if it is likely to cause physical harm, and/or likely to limit or deny access to community services, having a serious impact on the individual’s quality of life.

Examples

- Verbal, physical or sexual assault directed at others
- Self harm
- Property destruction
- Absconding
- Inappropriate eating behaviour – e.g. pica (eating non-edible items), eating raw or frozen food
- Inappropriate sexual behaviour (e.g. public masturbation)
- Hoarding
- Stealing
- Inappropriate hygiene (e.g. smearing faeces)
- Repetitive behaviour (e.g. pacing, repetitive questions)

People with ID who engage in challenging behaviour suffer serious consequences to their quality of life, with a range of possible negative physical and social outcomes:

- Pain from injury
- Malformation of face or limbs
- Loss of sight or hearing
- Being subject to restraint, medications or time out to manage behaviour
- Increased restriction and supervision (reduced opportunity to go out, suspension from work, etc)
- Additional neurological damage
- Social exclusion, neglect, and/or abuse
- Impact on staff
- Impact on families
- Even death

Summarise that challenging behaviours

- Are defined by their impact
- Are a social construct
- Have wide-ranging personal and social consequences
- Are descriptive, not diagnostic. Further investigation is required to understand the challenging behaviour and to formulate a management plan

### **Prevalence**

Challenging behaviours are common in people with ID, with a prevalence of 10-20% commonly reported in the literature (McClintock, Hall & Oliver 2003)

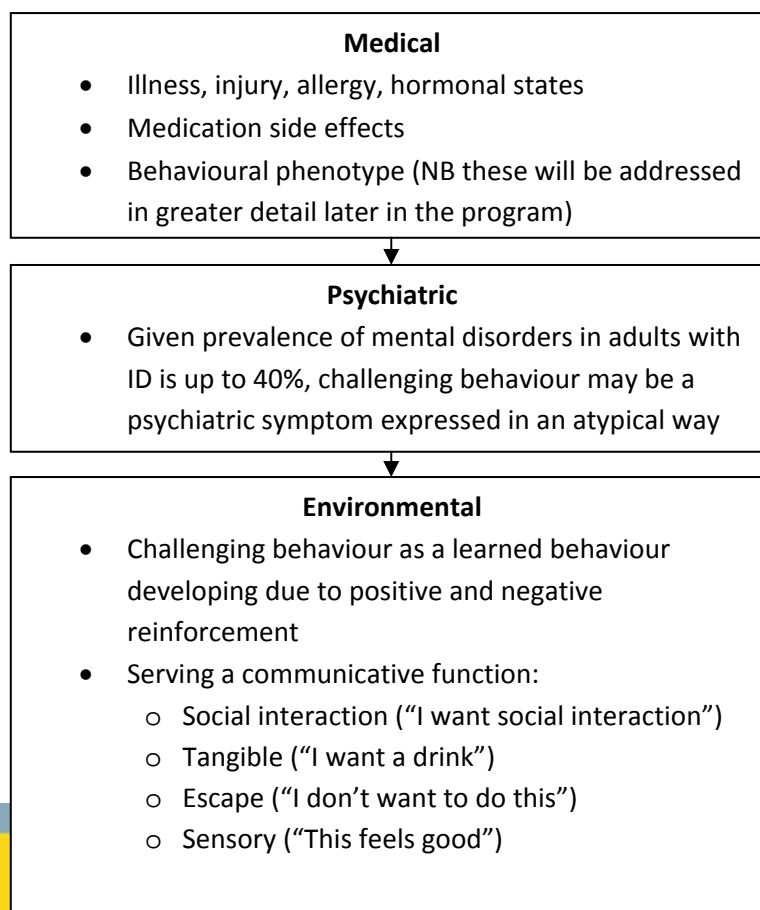
## Risk factors

- Degree of disability – those with severe/profound ID are more likely to demonstrate challenging behaviour than those with mild/moderate ID (Emerson, 2001; Holden & Gitleson, 2006; Hemmings et al. 2006)
- Male gender found to increase risk of challenging behaviour in people with ID by some (Emerson, 2001; McClintock et al 2003; Moss et al, 2000) but not all (Holden & Gitleson, 2006; Hemmings et al. 2006)
- Autism
- Age:
  - Rising during childhood, declining after school-leaving age.
  - Peak prevalence is in the 15-34 years range. (Emerson, 2001; Holden & Gitleson, 2006; Moss et al, 2000)
- Age x degree of disability interaction – in those with severe ID the decline in prevalence of challenging behaviour is only after 50+ years of age (Emerson, 2001)
- Poorer communication skills (Holden & Gitlesen 2006; Bott, Farmer & Rohde 1997; Carr & Durand, 1985)
- Degree of motor impairment (McClintock, Hall & Oliver 2003)
- Degree of sensory impairment (Emerson 2003)
- Medical conditions/pain (Bosch, Van Dyke, Milligan Smith & Poulton, 1997; Gunsett, Mullick, Fernald & Martin, 1989; Foley & McCutcheon 2004)
- Environmental stressors: living arrangements, life events, adversity/abuse (Emerson 2003; Simley et al. 2007)
- Underlying psychiatric conditions

## Aetiology

*How does challenging behaviour develop (ie, why does it occur)?*

A hierarchy for the order in which potential causes of challenging behaviour should be investigated/eliminated:



When a medical reason for a challenging behaviour has been ruled out, a possible psychiatric cause should be investigated and ruled out before it is assumed that the challenging behaviour falls into the “Environmental” category.

This hierarchy of causes are not mutually exclusive but present a guide for the investigation and treatment of factors underlying challenging behaviour. In reality, environmental (“behavioural”/learned) factors are likely to be relevant even where there is an underlying psychiatric or medical condition, and both should be taken into account. However it is important to rule out an underlying medical or psychiatric cause before a purely environmental approach is taken to the management of challenging behaviour.

### *Medical issues*

Pain and discomfort associated with different medical conditions can contribute to CB in adults with ID. In such cases the CB can be seen as a way of attempting to cope with the discomfort, and the connection between the medical condition and the resulting behaviour is not always predictable or obvious. Therefore thorough medical examination is required to rule out an untreated underlying medical condition, which when treated often results in a reduction in the CB.

- In eight out of 10 patients with severe to profound ID and CBs who were found to have underlying medical conditions ranging from broken bones, ear infections, impacted bowels, and hydrocephalus, behaviour problems decreased once the medical conditions were resolved (Gunsett et al., 1989)
- An underlying medical condition, previously undetected, was found in seven out of 25 patients with self injurious behaviour. In six cases, treating the condition resulted in decrease of the self injurious behaviour (Bosch et al., 1997)
- Foley and McCutcheon (2004) reviewed two cases where pain in people with severe ID and limited communication skills presented in such an idiosyncratic manner it was missed. The first involved a man who normally displayed obsessive compulsive behaviours (light switch flicking etc) but suddenly stopped doing these things for no apparent reason. Investigation revealed the man had five injured ribs. In the second case, a normally calm man very suddenly became verbally aggressive and non-cooperative. He was taken to emergency, but after admission appeared to show no signs of pain and so was left untreated. Sadly, it resulted in his death. The autopsy revealed septic shock and peritonitis of the small bowel caused by swallowing a coke-bottle top. These cases reveal the potential consequences of not investigating potential medical reasons for challenging behaviours or change in behaviour.
- Sleep disorders were associated with daytime behavioural problems in adults with ID (Brylewski & Wiggs, 1999)
- Gastrointestinal disorders are associated with behaviour problems in adults (Davidson et al., 2003) and GERD (Gastro-Esophageal Reflux Disorder) is associated with hand-mouthing (Swender et al., 2006), and with self-injury, aggression, fear/anxiety, screaming, depression and restlessness (Böhmer, Klinkenberg-Knol, & Neizen-de Boer 2002)

### *Psychiatric issues*

Research consistently shows an association between challenging behaviour and psychiatric symptoms, though findings regarding the relationship between specific behaviours and symptoms vary. For example (all points refer to findings in people with ID)

- CB associated with increased prevalence of psychiatric symptoms, especially anxiety and psychosis, but not significantly associated with depression (Holden & Gitlesen, 2003)
- Severity of CB associated with prevalence of psychiatric symptoms. The most marked association was with depression (cf Holden & Gitlesen, 2003), and anxiety was associated with self-injury (Moss et al 2000)

- Behaviour problems associated with psychiatric symptoms (not diagnoses) – in particular self-injury & aggression were associated with affective disorders (Hemmings, Gravestock, Pickard & Bouras, 2006)
- CB associated with higher psychopathology scores, and behavioural problems increased the likelihood of psychiatric conditions up to 3-fold in a sample with severe and profound ID (Rojahn et al, 2004). Two cases of challenging behaviour and bipolar disorder in which behaviour and psychiatric symptoms fluctuated together. In the first, self injurious behaviour was associated with depressive symptoms and in the second aggression was associated with mania (Lowry & Sovner 1992).

**Activity: challenging behaviours that may represent manifestations of psychiatric symptoms.**

Ask participants to fill out the columns in the table, and to consider how a mental disorder might cause the behaviour, describing the pathway from symptom to behaviour. Examples of misconstruing a behaviour as “challenging behaviour” might include “absconding”, “trying to get attention”, “non-compliance”, “oppositional behaviour” etc.

Behaviour	How it may be misconstrued as “challenging behaviour”	Possible underlying medical cause	Possible underlying psychiatric cause
Wandering or searching	Eg “Absconding”	Eg Delirium or cognitive impairment (uncommon)	Eg Anxiety, dissociation, psychosis
Complaining about aches and pains			
Outbursts of anger, eg property destruction			
Self harm, eg scratching at face or wrists until bleeding			
Refusing to participate in usual activities eg refusing to get on the bus for day program			
Screaming			
Exposing self			
etc			

**Managing Challenging Behaviour**

Management of CB depends on the cause of the behaviour:

- Primary medical cause: treating the medical issue should resolve the behaviour
- Primary psychiatric cause: treating the mental disorder through appropriate medication and psychosocial intervention, with possible specialised behavioural/environmental support, should alleviate the behaviour
- Primary environmental cause/a purely learned behaviour: specialised behavioural supports to substitute adaptive behaviours for the challenging behaviour

*Use of medication in management of challenging behaviour*

Outline of the role of medication in managing CB in the rare cases where psychosocial and environmental/behavioural interventions have been ineffective; this intervention is indicated only

infrequently, and usually where ID is more severe. The behaviour may have an underlying psychiatric cause, and there may be a learning/conditioned aspect to it as well, however due to the level of disability, the underlying cause may be harder to identify and specialised behavioural support may be less effective.

Outline the cautions that need to be considered when using medication to manage behaviour.

## **Assessment of Challenging Behaviour in adults with Intellectual Disability**

### *Mental Health Perspective*

Challenging behaviour is likely to come to the attention of mental health professionals during an acute escalated episode, when carers are unable to contain the behaviour and when it has already become ingrained and chronic. The setting may be during a visit to ED, or perhaps a support worker or carer will request a mental health referral to address the CB by addressing possible underlying mental health issues.

### *Triage*

- Acute onset challenging behaviour
  - Crisis
  - Thorough assessment
  - A full range of biological, psychological and social aspects need assessment
- Chronic challenging behaviour
  - Longer term challenge
  - Periodic review
  - Complex solutions
  - Multidisciplinary

## **Section 2: Behaviour management**

### **Specialised Behavioural Support**

#### *ADHC Behavioural Intervention Service (BIS)*

- Outline of the service provided by BIS – what does the BIS do?
- The kinds of cases and scenarios where BIS provides assistance

#### *Referral and assessment*

Outline the usual referral and assessment process that BIS engages in, including how mental health services and BIS would work together to assess and support a client who has challenging behaviour and who may have a mental health concern.

For example: GP & Behaviour Support practitioner do initial assessment to investigate possible medical cause → psychiatrist → specialist assessment service. Outline of CDDS. Outline exceptions to this sequence of assessment eg children/adolescents who have been to specialist assessment services many times; adult clients who go to Kogarah D&A for psychiatry services; CDDS offer assessment and treatment for mental health diagnoses as well; process depends on whether anyone has considered the possibility that the signs and symptoms might be indicative of a MH diagnosis, and/or whether they want to screen for a syndrome or autism etc first

### **Investigation process to rule out a psychiatric cause of the behaviour**

Outline the steps involved, and the professionals who can and should be involved in each task

- Collection of behavioural data over several weeks or months – ABC data (antecedent, behaviour, consequence) by family or carers at request of behaviour support practitioner

- Collection of data on sleep, appetite, mood by family or carers at request of behaviour support practitioner
- Psychiatry review – comprehensive screening for signs/symptoms of mental health diagnoses – client observation/interview, carer interview, review of ABC/sleep/mood/appetite data
- Hypothesis testing for possible functions of the behaviour if not psychiatric in nature?
- What happens if a psychiatric issue is found to be underlying the CB?
- How BIS works together with mental health services

*Even when a behaviour is a symptom of an underlying psychiatric condition, there may also be environmental factors involved.*

E.g. self harm may be a sign of depression, but may also be triggered and/or reinforced by reactions of others

### **Management of Challenging Behaviour**

Outline how BIS approaches the management of challenging behaviour. Include the possible role of mental health services in this process. Contrast the management plan for a scenario where the behaviour is “pure” CB with no underlying mental health or medical issue with a scenario of maladaptive learned behaviours in the context of mental health issues (eg threatening to burn down residential facility in order to express anger that is a symptom of depression).

*ADHC psychologists and behaviour support specialists assist with managing challenging behaviour.*

Assessment, functional analysis, development of strategies to assist families/staff to manage the behaviour when it occurs (“incident prevention and response plans”), skill building programs to teach new ways of achieving the same function (e.g. social stories teaching the person to ask for help rather than using challenging behaviour), counselling or other intervention.

- Incident prevention and response plans (IPRP’s) or “reactive strategies” – management strategies detailing a) prevention strategies, b) steps for managing the behaviour when it occurs, and c) strategies post-incident)
- Use the least restrictive to the most restrictive measures – e.g. first try redirection, then try PRN medication etc.
- IPRP’s sometimes contain – “Restricted Practices” – these are closely monitored, must have consent from legal guardian, and must be used in combination with positive strategies that focus on skill building. Restricted practices include: PRN medication, exclusionary time out, restricted access (e.g. to sharps, areas of the house, people, places, etc), seclusion, response cost, and physical restraint
- There are “prohibited practices” that are not able to be used legally – e.g. seclusion of people under 18 years; aversive practices that cause pain or discomfort or are demeaning, overcorrection
- Positive practices include: teaching coping strategies, teaching functionally-equivalent behaviour, strategies aimed at improving quality of life (more outings etc)

### **Group activity:**

Case scenarios for particularly confronting/difficult challenging behaviour – self injurious behaviour, and aggressive behaviour.

## Mental Disorders in Intellectual Disability – Legal and Ethical Considerations

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>7. Mental Disorders in Intellectual Disability – Legal and Ethical Considerations</b> <ul style="list-style-type: none"> <li>Duty of Care</li> <li>Mental Health Act 2007</li> <li>Decision Making <ul style="list-style-type: none"> <li>The Guardianship Act 1987</li> <li>The Powers of Attorney Act 2003</li> <li>Consent</li> <li>Assessing capacity to give consent</li> </ul> </li> </ul> Supporting the person who cannot give consent – similarities and differences to non-ID population	Participants understand and incorporate relevant ethical and legal considerations when working with clients with ID and comorbid mental disorder Participants understand when and how to liaise with substitute decision makers	The service's and the mental health professional's duty of care to a client with IDMH – differences compared with non-ID  How the MH Act 2007 relates to clients with IDMH  The decision-making process involving clients with IDMH  What is and is not consent  How decisions are made on behalf of those who lack the capacity to give consent  The role of the support worker and other professionals in consent	Assessing capacity to give consent  Supporting the person with IDMH who cannot give consent  Awareness of the mechanisms for substitute decision making  Awareness of privacy principles

*This module provides an introduction to the legal and ethical issues that are relevant when working with adults with an intellectual disability and mental health problems. The target audience is mental health workers who have a good understanding of the mental health act and a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

Legal and Ethical considerations when working with adults with intellectual disability and mental health problems centre around:

- Consent and decision making
- Risk and duty of care
- Privacy
- Discrimination

### **Consent**

Consent must be obtained whenever treatment involves invasive procedures or risks. Before treatment can proceed the professional must adequately disclose the proposed treatments, risks, benefits, side effects and reasonable alternatives, and must be satisfied that the client is able to consent, and does so freely and voluntarily. People with ID have the same rights as everyone else, including making their own decisions. However sometimes people with ID may need more support to make decisions, and in some cases may lack the capacity to make decisions. There are legal guidelines for how decisions should be made when someone is unable to give consent.

The Mental Health Act (2007) applies to people with ID in the same way that it applies to people without ID. Also relevant is the NSW legislation:

- The Guardianship Act 1987
- The Powers of Attorney Act 2003

### *Assessing capacity to give consent*

- Assess whether the person understands the nature of the decision
- Assess knowledge of risks
- Consider why the person has come to that decision
- Assess after a sufficient period of time for processing of the information
- Do not demand a high level understanding or complex decision making
- Cognitive functioning and suggestibility may also be assessed by a psychologist
- Does the person understand the effects of the treatment or procedure?
- Does the person understand the consequences of not having the treatment or procedure?
- Are there other options available?

### *Guardianship*

- Definition and role of a 'person responsible' – what they can and cannot consent to
- Legal Guardians – application process (i.e. applications for guardianship go through the Guardianship Tribunal (GT)). A hearing follows where a decision is made about whether guardianship is required, who will be the guardian (e.g. family member, friend, public guardian), for what decision making 'functions', and for how long (until another review by the GT)
- Functions include: medical and dental, services, restricted practices, financial management, accommodation. Include information about each of these.
- The public guardian will consult with the service user in making the decision.
- Urgent, minor, major and special medical treatments – definitions of each and who is able to consent to them (e.g. only the GT can consent to special medical treatments and any medical treatment that the service user or person responsible objects to)
- The relationships between other state-based departments and or services in the legal and ethical considerations of dealing with an individual with IDMH

### **Risk and duty of care**

If someone has a mental health problem, there may be increased risk of:

- vulnerability or exploitation
- self-neglect
- suicide and self-harm



- contact with the criminal justice system.

This has legal and ethical implications for those working with people with ID and mental health problems

*NSW Law – Civil Liability Act 2002 No 22; Division 2 Duty of care*

#### 5B General principles

- (1) A person is not negligent in failing to take precautions against a risk of harm unless:
  - (a) the risk was foreseeable (that is, it is a risk of which the person knew or ought to have known), and
  - (b) the risk was not insignificant, and
  - (c) in the circumstances, a reasonable person in the person's position would have taken those precautions.
  
- (2) In determining whether a reasonable person would have taken precautions against a risk of harm, the court is to consider the following (amongst other relevant things):
  - (a) the probability that the harm would occur if care were not taken,
  - (b) the likely seriousness of the harm,
  - (c) the burden of taking precautions to avoid the risk of harm,
  - (d) the social utility of the activity that creates the risk of harm.

**Harm** means harm of any kind, including the following:

- (a) personal injury or death,
- (b) damage to property,
- (c) economic loss.

**Negligence** means failure to exercise reasonable care and skill.

Relevant NSW legislation:

- Civil Liability Act 2002
- Occupational Health and Safety Act 2000
- Children and Young Persons (Care and Protection) Act 1998

#### **Privacy**

While providing care to someone with an ID is likely to involve communicating with others who may be providing care to the service user, it is important to be mindful that the entitlement to privacy.

Discuss the complexity involved, and how the duty of care can be balanced with the right to privacy.

The importance of communication and building a relationship with the service user.

NSW legislation:

- Privacy and Personal Information Protection Act 1998

#### **Discrimination**

Adults with ID are at increased risk of discrimination that not only has a detrimental effect on their happiness and quality of life, but which may also be illegal.

NSW legislation:

- Disability Services Act 1993
- Anti-Discrimination Act 1997

## Mental Disorders in Intellectual Disability – Lifespan and Transition Issues

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>8. Mental Disorders in Intellectual Disability – Lifespan and Transition Issues</b> <ul style="list-style-type: none"> <li>Children &amp; young people with ID               <ul style="list-style-type: none"> <li>Vulnerabilities to mental disorder</li> <li>Presentation of mental disorder</li> <li>Family and social issues</li> </ul> </li> <li>Older people with ID               <ul style="list-style-type: none"> <li>Vulnerabilities compared with non-ID population</li> <li>Dementia and other mental disorders</li> </ul> </li> </ul>	Participants will develop an understanding of lifespan and transition issues in clients with ID and comorbid mental disorder	<p>Issues associated with transitions between life-stages; key vulnerabilities to mental disorders associated with same.</p> <p>Mental disorders &amp; dementia in older people with ID.</p> <p>Mental disorders in younger people with ID.</p> <p>Mental disorders in children with ID.</p>	<p>Identify vulnerabilities to mental disorder in people with ID going through certain life changes.</p> <p>Identify vulnerabilities to mental disorder in people with ID in certain age-groups</p>

*This module covers specific issues relating life-span and transition issues for adults with ID and mental health problems. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

There are certain periods in the lifespan, and certain transitions, that all people may experience as stressful, or that are associated with increased risk of developing certain mental health problems.

Emphasise that most with an intellectual disability have a mild intellectual disability and resemble the normal population in how they respond to life-span and transition issues, however due to the associated social, health, and interpersonal difficulties may be more vulnerable during important life transitions. Remind participants they already have the skills on which to build more specialised skills for this population.

**Transition Periods, including those of particular vulnerability for those with ID**

- Initial diagnosis of ID
- Starting school
- Primary to high school
- Reaching puberty

- Adult sexual relationships
- Finishing school – starting work, post-school options or day program
- Moving from the family home
- Moving from one residence to another
- Menopause
- Death of parents
- Older age
- End of life decisions

### **Specific Vulnerabilities**

#### *Children and Young People*

Children with ID are at risk of being more:

- dependent on others for help in acquiring basic skills
- prone to physical difficulties
- prone to emotional and behavioural disturbance
- prone to social stigmatisation and its consequences.

They have complex social, medical, familial, educational, behavioural and cognitive needs.

The importance of diagnosis

- Individual's and family's basic right to know
- Relief from uncertainty as to cause of problem
- Relief from guilt regarding cause of learning disabilities and developmental/behavioural problems
- Facilitation of grief resolution
- Focusing towards future
- Genetic counselling
- Instigation of interventions relevant to strengths and needs
- Identifying with and belonging to support group
- Identifying any associated conditions

Cover the causes of emotional disturbances – constitutional, medical, developmental, cognitive, familial, social, educational.

Note the necessity of paediatricians in assessment and management and continuing monitoring from family GPs.

Referrals to specialists, allied health and other supports important in a holistic approach of care .

The importance of keeping an accurate medical history. Keeping a medical and personal record gives practitioners longitudinal information which affects future treatment.

Family and social issues: Families are often unequipped to cope with a special needs child, causing stress and tension amongst the family. Child with ID may not have access to external supports due to family financial strain, cultural differences restricting seeking assistance or fear of state services.

As a result of these stressors the child may not receive enough developmental support (eg parents not engaging with child enough) which can lead the mental health concerns.

Children with ID traditionally receive more supports than adults do. It can be difficult for families to adjust from having their child in schooling five days a week to then potentially having no or limited options for what their child can do when schooling is completed. Some go into programs offered by ADHC or NGOs, some find employment – but many find this transition extremely difficult. This will have significant affects on the young adult's mental health, especially if they are not in a position to maintain the social networks they had at school.

Similarly as each stage of the life span continues, the person may feel isolated if they have not formed their social networks and are still relying on that of their familial networks from when they were a child – or worse still, only the professionals they come into contact with through the care system whom they are not permitted to befriend or love socially.

#### *Older people with ID*

Often for older people with ID, the GP becomes the most consistent practitioner. As a result it is important that the GP is able to tell the difference between the wishes of the patient with ID and their carers'.

Life spans are increasing due to improved medical advancements, although service support systems may not be keeping up. The ageing parents/carers population is becoming a significant challenge, as these parents have taken life-long responsibility of their children with intellectual disability, who are well into adulthood by the time they reach old age. These parents are at a stage in their lifespan where they can no longer function as carers, and both generations suffer from lack of support and assistance. As a result, some people with ID find themselves introduced into the world of community services as aged people themselves, with no contextual understanding of how the service or medical systems operate.

Also address dementia – early/middle/late stages:

- Strong association between Down Syndrome and dementia (Oliver & Holland 1986; Holland & Oliver 1995)
- Differential diagnosis
  - Depression
  - Other mental health/psychological problems
  - Thyroid problems
  - Sensory difficulties
  - Other physical problems (eg acute infections, neurological problems)
  - Environmental and social factors
  - Effects of poly-pharmacy

#### *Making environmental, social and cognitive changes to cope*

Proactive measures, clear communication, ensuring the person understands what is expected of them, using a reminder system, keeping the medical and personal health records updated, going for annual check-ups, learning about their own body and its needs, monitoring lifestyle/choices and going for regular dental checks.

## MODULE 9

### Mental Disorders in Intellectual Disability – Personality Disorders, Forensic, and D&A Issues

#### Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>9. Mental Disorders in Intellectual Disability – Personality Disorders, Forensic, and D&amp;A Issues</b> <ul style="list-style-type: none"><li>• Personality disorders in intellectual disability</li><li>• Offending behaviour in intellectual disability</li><li>• D&amp;A issues in intellectual disability</li></ul>	Participants will develop an understanding of personality disorders, forensic and D&A issues associated with ID and comorbid mental disorder	Offending and D&A use in people with ID and mental disorders – differences compared with non-ID.  Personality disorders in people with ID – differences compared with non-ID  Relationship between mental disorder and offending and D&A use in ID population.	

*This module covers Personality Disorders, Forensic issues, and substance abuse in adults with ID and mental health problems. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

Most with an intellectual disability have a mild intellectual disability, and resemble the normal population in presentation and treatment needs for personality disorders and D&A issues and in considerations around forensic issues. Emphasise that participants already have the skills template on which to build more specialised skills for this population.

#### Personality Disorders

Research difficulties:

- Variable sample characteristics
- Variable diagnostic mechanisms/criteria used
- Questionable validity of the diagnostic instruments used
- As a result, prevalence estimates range from 22% to 92% (van den Hazel, Didden & Korzilius, 2008)

Conceptual difficulties:

- Some features inherent to ID may meet some criteria for a PD, eg “allowing others to make most of one’s important life decisions” (Torr, 2003)
- Certain maladaptive behaviours and emotional responses and related social and occupational impairments may be due to communication and cognitive impairments rather than personality

However it is clinically and conceptually useful and important to consider Personality Disorders in adults with ID when these caveats are taken into account.

Generally it is agreed that PD can only be diagnosed over the age of 21 years and in adults with only mild ID.

#### *Borderline Personality Disorder*

- Estimate of prevalence if available
- Comment on the risks and features of clinical significance associated with BPD in ID especially any that vary to BPD in those without ID
- Management options – similarities & differences compared with non-ID population and adjustments to make therapeutic intervention more accessible to those with ID

#### *Antisocial Personality Disorder*

- Estimate of prevalence if available
- Comment on the risks and features of clinical significance associated with APD in ID especially any that vary to APD in those without ID
- Management options – similarities & differences compared with non-ID population and adjustments to make therapeutic intervention more accessible to those with ID

#### *Other Personality Disorders*

- Estimate of prevalence if available
- Comment on the risks and features of clinical significance associated with other PDs in ID especially any that vary to other PDs in those without ID
- Management options – similarities & differences compared with non-ID population and adjustments to make therapeutic intervention more accessible to those with ID

#### **Substance Abuse**

Research into substance abuse in people with ID is scarce. Though people with ID are less likely to use substances than those without ID, for those that do use substances the rate of abuse is considerably higher.

Risk factors for substance abuse include being young, male, having borderline/mild ID, living alone, and having a mental health problem.

## Offending behaviour/forensic issues

Difficulties in researching offending behaviour in this population – most minor crimes are probably not recorded, as well as the difficulties that arise in all areas of research to do with research design and definitions/classification criteria. Researchers disagree about the prevalence of intellectual disability within the criminal justice system – some stating that it is unclear whether people with ID are more or less likely to offend than people without ID, while others conclude that generally people with ID seem to be over-represented in the criminal justice system. If people with ID are indeed over-represented, reasons may be:

- Possible actual higher rate of offending behaviour; OR
- Increased vulnerability within the CJS eg more easily arrested, or confess more readily

Representation in prisons is lower than in police stations. People with ID are at a disadvantage in the criminal justice system (due to being more suggestible and acquiescent under questioning, being more likely to make false confessions, having a decreased understanding of rights and of the legal process), and are at increased vulnerability of victimisation in prison.

There seems to be a high prevalence of mental health needs amongst people with ID who have committed offences (Noble and Conley, 1992; McGee and Menolascino, 1992), and they may be less likely to be abusing substances than offenders without ID (MacEachron 1979). Other characteristics of those with ID who have offended are similar to characteristics of offenders without ID:

- High incidence of social deprivation and family breakdown/disorder in childhood
- Long histories of anti-social behaviour
- High rates of adult unemployment
- Be younger
- Be male

### *“Challenging” or “offending” behaviour?*

Technically, when an offence is committed, a person is not necessarily guilty of a crime. For a person to be proven guilty, they must be proven to have done the act, AND to have a “guilty mind”. Having an intellectual disability is taken into account when courts examine whether the offender had a “guilty mind”. The majority of offences committed by people with ID are considered “challenging behaviour” (ie not involving a “guilty mind”) and never come to the attention of the courts. Even if they do, and the person is found guilty, the judge may take the ID into account as a mitigating circumstance. Generally, the milder the ID, or the more serious the offence, the more likely that the criminal justice system will be involved.

Also relevant are the capacity to consent and the capacity to make decisions, capacity to participate in the legal process, and the reliability of people with ID as witnesses.

## Mental Disorders in Other Developmental Disabilities – Specific Vulnerabilities

## Information framework for presenters

MENTAL DISORDERS IN INTELLECTUAL DISABILITY – WORKSHOP 2			
Module & Topics	Learning Objectives	Knowledge	Skills
<b>10. Mental Disorders in Other Developmental Disabilities – Specific Vulnerabilities</b> <ul style="list-style-type: none"> <li>Autism Spectrum Disorders               <ul style="list-style-type: none"> <li>Definition, description, functional effects, causes</li> <li>Vulnerability to MH issues</li> <li>Presentation of MH issues</li> <li>Enhancing communication</li> </ul> </li> <li>Down Syndrome and other important behavioural phenotypes with MH vulnerabilities.</li> </ul>	Participants will be able to understand the presentation and management of mental disorders in people with other developmental disabilities	Presentation of ASDs  Mental disorders in ASD – presentation and management  Strategies to improve communication  Vulnerability to dementia in Down Syndrome	Adapt communication to facilitate exchange of information with people with ASD  Investigate presence of mental disorder in people with ASD  Identify vulnerabilities to mental disorder in ASD

*This module covers Developmental Disabilities and the specific vulnerability of different syndromes to mental health problems. The target audience is mental health workers who have a basic understanding of the concepts, causes, and prevalence of intellectual disability and mental disorders in intellectual disability.*

**Definitions of Developmental Disability**

Define Developmental Disability. This module will not cover all developmental disabilities, but will address some of the more common syndromes that fall into this category of disability, and which have associated mental health vulnerabilities.

A developmental disability will not necessarily be associated with an intellectual disability.

Pervasive Developmental Disorders – includes: autistic disorder, Rett’s syndrome, childhood disintegrative disorder, Asperger’s syndrome, and pervasive developmental disorder – nos.

PDD is characterised by delay and deviance in the development of social, communicative, and other skills.



## Autistic Disorder

In DSM-I and II, it was considered to be on the same continuum as childhood schizophrenia – however this assumption has been disregarded.

Features include:

- Marked and sustained impairment in social interaction - present by age 3 years, if not before.
- 30-40% never use language for communication. Delay in language acquisition often noted by parents from 12 months onwards.
- Approx. 50% have an ID
- Often have difficulty tolerating changes to routine; often display stereotyped movements such as hand flapping; may develop interest in repetitive activity (e.g. spinning tops)
- Mood lability and inappropriate affect, self injurious behaviour, sleep and eating problems are all common.

Prevalence rates vary from 4.5 per 10,000 (Kanner, 1966) to 30.8 per 10,000 (Baird et al, 2002) – prevalence rates are increasing but may be partly due to increased case detection.

Male:female ratio approx 4:1

No known cause, however family and twin studies highlighted a strong genetic component to etiology, but no single gene identified. No evidence that MMR immunisation causes autism. Evidence that the amygdala of the brain is different.

Associated with other genetic conditions, most notably Fragile X. Seizure disorder common.

Many theories re: social dysfunction but most accepted is that people with autism have difficulty inferring the thoughts and motivations of others, and fail to predict others behaviour and adjust accordingly, leading to a lack of reciprocity in communication.

### *Autism and Mental health*

People with autism are at higher risk for developing mental disorders, most notably depression (Howlin, 1997) and anxiety (Cath et al, 2008). Very difficult to find prevalence rates of ASD and mental health diagnoses.

Enhancing communication – e.g. script fading, picture exchange communication system (PECS), early intervention programs aimed at improving eye contact, gesture and vocalisation.

## Behavioural Phenotypes

### *Definition*

The set of physical characteristics produced by a particular genetic abnormality (a “genotype”) is known as the “phenotype” of the syndrome. “**Behavioural** phenotype” is a term denoting a behaviour or a set of behaviours that are determined by a genotype:

“A characteristic pattern of motor, cognitive, linguistic and/or social abnormalities which is consistently associated with a biological disorder.”

(The Society for the Study of Behavioural Phenotype, <http://www.ssbp.co.uk>).

There appears to be a core set of deficits in adaptive functioning that is common to all developmental disabilities. These are not considered part of a behavioural phenotype. However there are specific patterns of abilities and deficits associated with known genetic syndromes, and these are known as behavioural phenotypes.

### *Syndromes and associated behavioural phenotypes*

Outline clinical features, behavioural phenotype and mental health vulnerabilities of a selection of the following disorders; more detailed information on each disorder can be pulled together from OMIM to be included as an appendix.

#### Down Syndrome

Overall prevalence of mental ill-health is lower in people with Down Syndrome compared to other adults with intellectual disability (Mantry, Cooper, *et al*, 2008).

Incidence of mental ill-health in Down Syndrome is around 10.8 - 23.7% (depending on clinical assessment/diagnostic criteria used). Highest incidence found by Mantry, Cooper *et al* (2008) was depressive episode and dementia (both 5.2%)

#### Fragile X

Almost all males who have Fragile X have an intellectual disability, usually in the moderate range, whereas only 1/3 - 1/2 of females with Fragile X have an ID. There is a strong overlap with diagnostic criteria for autism.

Males with fragile X often display hyperactivity and distractibility, irritability, repetitive stereotyped movements, pronounced gaze aversion, and social anxiety. Face-to-face gaze is associated with hyperarousal and high levels of stress.

Females can display mood dysregulation, often seen as chronic depressed mood, and poor organisational skills and impulsivity.  
(all from Feinstein & Chahal, 2009)

#### Fetal Alcohol Syndrome

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

#### Fragile X Syndrome

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

#### Prader-Willi Syndrome

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

#### Tuberous Sclerosis Complex

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

#### Velocardiofacial Syndrome

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

#### Williams Syndrome

Information concerning clinical features, behavioural phenotype and mental health vulnerabilities can be provided on request

## Appendix 4 Guidelines for presenters

Template for *Workshop 1: Fundamentals* provided as an example:

### MENTAL DISORDERS IN INTELLECTUAL DISABILITY EDUCATION WORKSHOPS

## Guidelines for presenters

Thank you for agreeing to present <topic> at the workshop *Mental Disorders in Intellectual Disability*, which we (the Department of Developmental Disability Neuropsychiatry) are holding in partnership with South Eastern Sydney Illawarra Health Service (SESIAHS). Your presentation will be at <time> on the following dates:

Date	Location
31 <sup>st</sup> August 2010	St George Hospital
10 <sup>th</sup> Sept 2010	POW Hospital
17 <sup>th</sup> Sept 2010	Wollongong Hospital

You are welcome to attend for all or part of the day.

### Context

The workshop will be attended by up to 40 adult mental health staff such as psychiatrists, social workers, psychologists, mental health nurses and occupational therapists. Your presentation is part of a day long program designed to provide a thorough introduction to mental disorders in adults with intellectual disability.

The topics covered in this workshop are:

1. Introduction to Intellectual Disability
2. Mental Disorders in Intellectual Disability – Introduction
3. Mental Disorders in Intellectual Disability – Communication and Assessment
4. Agencies Involved in Supporting People with Intellectual Disability
5. Mental Disorders in Intellectual Disability – Management

For more information see attached *Project outline* and *Program*.

### Your Presentation

Below are some guidelines for developing your presentation.

#### Duration

<time> has been allocated for your presentation.

## *Content*

Refer to attached *Information Framework* document, which contains all the information that your presentation should cover at a minimum. Please add further information to support the points provided as you see fit.

## *Style*

Ways to support participant engagement with and retention of the information you present include

- making your presentation interactive – with audience involvement, eg using any of
  - brainstorming
  - small group activities or pair work
  - case studies
- using a variety of formats, eg slides; video; handouts; whiteboards
- highlighting participants' existing high level of skill and knowledge in mental health, and noting that the material you are presenting extends and builds on their existing resources and competence
- making sure your presentation suits your style and is comfortable for you

## *Slides*

Please prepare your slides using the template provided. Some general suggestions you may wish to follow to support the structure of your presentation include:

- begin with a slide stating the objectives of your module
- conclude the presentation by asking participants about the extent to which they feel the objectives have been met

## *Assistance*

We can provide you with as much or as little support as you require to develop your presentation. For example we can provide:

- ideas for interactive participant activities
- case studies and selected videos
- slides
- detailed information to extend any section of the information framework.

Please contact us as soon as possible for any support you require.

## **Video recording**

We would like to record one of the workshops and use the footage as part of other educational resources. If you consent to being recorded, please complete the attached *Appearance Release* form and fax it to 02 9931 9154. Please inform Thea or Lee (details below) if you do not consent to being recorded.

## **Slides**

We would like to print your slides as handouts for workshop participants. It is also possible that your slides may be used as part of future training resources used in other settings, eg being made

available on the NSW Health intranet or to professional bodies such as the Royal Australian & New Zealand College of Psychiatrists. Please email Thea or Lee (details below) if you do not consent to either use of your slides.

### **Next steps**

We need the following from you by Tuesday 24<sup>th</sup> August 2010:

- your slides in electronic format
- any extra audio-visual requirements for your presentation (eg white board, hand outs etc)
- your biographical information, including title, current role and organisation, and a brief history of your experience and expertise.

### **Contacts**

Ms Thea Kremser Ph: (02) 9385 2580 Fax: (02) 9931 9154 Email: <a href="mailto:t.kremser@unsw.edu.au">t.kremser@unsw.edu.au</a>	Ms Lee Wilson Ph: (02) 9931 9153 Fax: (02) 9931 9154 Email: <a href="mailto:l.wilson@unsw.edu.au">l.wilson@unsw.edu.au</a>
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## Appendix 5 Presenter Biographies

### Workshop 1: Fundamentals

*Associate Professor Julian Trollor (Module 1: Introduction to Intellectual Disability; Module 2: Mental Disorders in Intellectual Disability – Introduction)*

Julian is a Neuropsychiatrist who holds the inaugural Chair of Intellectual Disability Mental Health at the University of New South Wales. He has recently established the Department of Developmental Disability Neuropsychiatry, which aims to improve the mental health of people with intellectual disability by training health professionals, undertaking research and engaging in service and policy development in this area. He is involved in diverse research programs including: aging and cognitive decline in intellectual disability, complex genetic disorders and intellectual disability, intellectual disability in the criminal justice system, human rights & healthcare in intellectual disability, and ageing studies in the general population. The newly established Department is supported by the Department of Human Services (Ageing Disability and Home Care) and the Faculty of Medicine at UNSW. The Department also liaises closely with NSW Health, professional groups and Peak Bodies to achieve its aims.

*Mr Michael Bartels (Module 1: Introduction to Intellectual Disability)*

Michael is the Deputy Chairperson of the NSW Council for Intellectual Disability (CID). He has played cricket for NSW in the Lord's Taverners Shield for people with an intellectual disability for the last nine years, and has represented Australia in the Australian Allstars Team. Michael is dedicated to giving people with intellectual disability better rights and services.

*Ms Fiona McKenzie (Module 1: Introduction to Intellectual Disability)*

Fiona is a member of the Board of Directors at NSW Council for Intellectual Disability. She is committed to completing the annual City2Surf, and is also a baker's assistant, rising every day at 4:30AM to start work. Fiona is involved with a new group called SWB@CID (Secret Women's Business at the Council for Intellectual Disability), where women with intellectual disability meet and discuss important issues in a comfortable environment.

*Ms Annette Elias (Module 3: Communication and Assessment)*

Annette Elias is a Speech Pathologist and Behaviour Support Specialist in the Regional Behaviour Intervention Team (RBIT) of Ageing, Disability and Homecare (ADHC), which is part of the Department of Human Services NSW. She has worked with the Department since completing her university degree in 2005. As a result, all her experience has been with clients with an Intellectual Disability. She started work on the community team providing direct therapy to clients with communication impairments, and has recently moved to the Regional Behaviour Intervention Team. Here her focus is on positive behaviour support to clients with severe challenging behaviours and an intellectual disability.

*Ms Tanya Brunette (Module 3: Communication and Assessment)*

Tanya Brunette is a Psychologist and Behaviour Support Specialist in the RBIT of ADHC. She has experience in disability, mental health, counselling and organisational psychology services, and is completing an MPsych (Counselling) degree. She began in disability services from the ground up,

starting as a social educator in group homes where she provided assistance with daily living. In her current role she provides behaviour support services to a range of people with an intellectual disability and with co-occurring mental health needs.

*Ms Alison Hart (Module 4: Agencies Involved in Supporting People with Intellectual Disability, Wollongong and St George Hospitals)*

Alison Hart is the Manager, Information Referral and Intake (IRI) for ADHC, Metro South Region. She has been in this role at IRI for the last 18 months, managing the "Front Door" of ADHC-run and ADHC-funded organisations in the Region. This includes managing vacancies for those who are "homeless" – some of whom have a dual diagnosis. Alison has worked in Disability Services for 25 years, starting when Disability was part of Health. During this time she has worked as a Psychologist in the Community Support Teams, providing counselling and developing Behaviour Support Plans for people with disabilities and their families living in the community and working directly with people with a dual diagnosis. For 10 years Alison worked in ADHC Learning and Development, providing training to staff in a many areas including working with those with a dual diagnosis. Alison also spent four years as Senior Behaviour Support Specialist with the Regional Behaviour Intervention Team in Metro South. In this role she supported clinicians working in the area of behaviour support for clients with complex cases, including those with a dual diagnosis.

*Ms Sue Day (Module 4: Agencies Involved in Supporting People with Intellectual Disability, Prince of Wales Hospital)*

Sue Day is a Senior Project Officer at Information Referral and Intake (IRI) for ADHC, Metro South Region. She supervises the *Leaving Care* and *Vacancy Management* projects, and has worked in IRI for the past four years. IRI is responsible for managing vacancies in Supported Accommodation for those who have a disability and are homeless, including those with a dual diagnosis. Sue has worked in Disability Services for 20 years, starting when Disability was part of Health. During this time she has worked in and managed supported accommodation and respite services for people with an intellectual disability.

## **Workshop 2: Advanced**

*Ms Tara Carthy (Module 6: Challenging Behaviour)*

Tara has worked as a Behaviour Support Specialist in the disability field for 10 years. She has worked in the government and non government sector, and is currently working with ADHC's Regional Behaviour Intervention Team as a Senior Behaviour Support Specialist providing specialist behaviour support to ADHC direct and funded services. Tara completed a Masters Degree of Health Science (in Developmental Disability) through the University of Sydney, and undergraduate studies in Social Science. Tara is a certified Professional Assault Response Trainer and has a special interest in forensic disabilities and Autism Spectrum Disorders. Tara has completed a research project on men with mild intellectual disabilities who sexually offend, where she investigated the prevalence of sexually abusive behaviour and common characteristics found in this population as well as the efficacy of available sex offender treatment programs. Tara is currently involved in a joint (ADHC/Health/DET) retrospective study of behavioural/medical clinics used in the DET system



*Associate Professor Julian Trollor (Module 6: Challenging Behaviour; Module 8: Lifespan and Transition Issues)*

Julian is a Neuropsychiatrist who holds the inaugural Chair of Intellectual Disability Mental Health at the University of New South Wales (UNSW). He has recently established the Department of Developmental Disability Neuropsychiatry, which aims to improve the mental health of people with intellectual disability by training health professionals, undertaking research and engaging in service and policy development in this area. He is involved in diverse research programs including: aging and cognitive decline in intellectual disability, complex genetic disorders and intellectual disability, intellectual disability in the criminal justice system, human rights & healthcare in intellectual disability, and ageing studies in the general population. The newly established Department is supported by the Department of Human Services (Ageing Disability and Home Care) and the Faculty of Medicine at UNSW. The Department also liaises closely with NSW Health, professional groups and Peak Bodies to achieve its aims.

*Ms Melanie Oxenham (Module 7: Legal and Ethical Considerations)*

Melanie is the Manager of Information and Support at the Public Guardian. She graduated as a Social Worker in 1986, and has spent the majority of her working life in disability services. She has worked at the Public Guardian for the past 13 years, with 10 years experience as a guardian and Regional Manager before moving into the Information and Support Team. She is also an Official Community Visitor, and visits a number of government and non-government group homes in Western Sydney. She also teaches Disability Work at TAFE. The Public Guardian is an independent statutory authority, who is supported administratively by the NSW Trustee and Guardian. The Information and Support Team provides information to the community about guardianship via our telephone enquiry line, website, publications and community education presentations. The team also includes the Private Guardian Support Unit, which provides information and support to private and enduring guardians. The Information and Support Team is responsible for taking feedback from our stakeholders, including managing complaints and requests for reviews of decisions.

*Ms Kim Walker (Module 8: Lifespan and Transition Issues)*

Kim works with the NSW Council for Intellectual Disability (CID) to develop easy-to-read information for people with an intellectual disability. Her major work has involved developing health fact sheets. Kim also worked for 17½ years providing education and developing easy-to-read resources for people with an intellectual disability at the Intellectual Disability Rights Service. Kim is passionate about advocating for the rights of people with an intellectual disability, and regularly speaks on behalf of NSW CID to people with an intellectual disability, disability workers, and other professionals.

*Mr Matt Frize (Module 9: Personality Disorders and Offending Behaviour)*

Matt is the Team Leader, Practice Development of ADHC's Community Justice Program, and works on the Family Therapy Team at Westmead Children's Hospital. He is a registered Psychologist, has a Masters in Educational & Developmental Psychology, and is this year completing a Doctorate in Clinical Psychology. Matt is also currently completing a PhD at the University of Sydney on the topic of intellectually disabled offender risk assessment and management. He has worked as a Residential Support Worker, behaviour intervention clinician, and clinical team leader in the disability industry in government and non-government organisations. He is also experienced in the delivery of Dialectical Behaviour Therapy through Bankstown's Community Mental Health Service, and is currently

implementing a trial in a Systemic approach to DBT for people with an intellectual disability and their support systems. Matt is on the Executive Committee for PsychDD, ANZAPPL and the NSW Branch of the APS's College of Forensic Psychologists.

*Professor Rhoshel Lenroot, MD (Module 10: Mental Disorders in Other Developmental Disabilities)*

Rhoshel is the Clinical Director of Child and Adolescent Mental Health Services for the South Eastern Sydney and Illawarra Area Health Service, a Research Fellow with Neuroscience Research Australia, and the Chair of Infant, Child and Adolescent Psychiatry at UNSW. Rhoshel received her medical degree and training in Adult, Child, and Adolescent Psychiatry at the University of New Mexico in the United States. She began her work in psychiatric research in New Mexico studying adolescents with schizophrenia. She then joined the Child Psychiatry Branch of the National Institutes of Mental Health. In May of 2009 Rhoshel relocated to Sydney. Her work here is focused on neuroimaging studies of brain development, how the development of social cognition is disturbed in disorders such as autism and schizophrenia, and improving mental health interventions for children and adolescents.

## Appendix 6 Evaluation Form

Evaluation Form for *Workshop 1: Fundamentals* at Prince of Wales Hospital provided as an example.

Page 1:

Mental Disorders in Intellectual Disability – Workshop 1, Prince of Wales Hospital 10/09/10					
EVALUATION FORM					
<p>We would appreciate your feedback. Please place a tick for each question in the table below, and circle the best answer in the remaining questions.</p>					
Please rate the success of the workshop in improving your knowledge and confidence in these areas: (please tick)	Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
The health, social and psychological issues associated with intellectual disability					
The complexity and variety of intellectual disability and its associated syndromes					
The presentation of mental health problems in adults with an intellectual disability					
Communication and assessment strategies for adults with intellectual disability and mental disorders					
Clinical management of clients with intellectual disability and comorbid mental disorder					
Referring to and working with ADHC and other associated agencies					
<p>Which session/s did you find <b>most</b> useful? (please circle)</p> <p>Why?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>					
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;"> <p>1. Introduction to Intellectual Disability</p> <p>2. Mental Disorders in Intellectual Disability – Introduction</p> <p>3. Communication and Assessment</p> <p>4. Agencies Involved in Supporting People with Intellectual Disability</p> <p>5. Management</p> </div> <div style="width: 45%; border-left: 1px solid black; padding-left: 10px;"> <p>1. Introduction to Intellectual Disability</p> <p>2. Mental Disorders in Intellectual Disability – Introduction</p> <p>3. Communication and Assessment</p> <p>4. Agencies Involved in Supporting People with Intellectual Disability</p> <p>5. Management</p> </div> </div>					
<p>Which (if any) session/s did you find <b>least</b> useful?</p> <p>Why?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>					
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;"> <p>1. Introduction to Intellectual Disability</p> <p>2. Mental Disorders in Intellectual Disability – Introduction</p> <p>3. Communication and Assessment</p> <p>4. Agencies Involved in Supporting People with Intellectual Disability</p> <p>5. Management</p> </div> <div style="width: 45%; border-left: 1px solid black; padding-left: 10px;"> <p>1. Introduction to Intellectual Disability</p> <p>2. Mental Disorders in Intellectual Disability – Introduction</p> <p>3. Communication and Assessment</p> <p>4. Agencies Involved in Supporting People with Intellectual Disability</p> <p>5. Management</p> </div> </div>					
<p>How easy was the information to understand (please circle)</p> <p>Comments:</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>					

How would you rate **Julian Trollor's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Michael Bartels's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Fiona McKenzie's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Annette Elias's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Tanya Brunette's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Sue Day's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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How would you rate **Thea Kremser's** style of presentation?

Very unsatisfactory	Unsatisfactory	Satisfactory	Good	Excellent
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Comments:

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Any other comments:

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