

## Responsibilities and Rights for Consumers and their Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW.

### *Draft Health Guideline for Health Service Consumers with Intellectual Disability.*

*David Dossetor and the Models of Care Subcommittee of the NSW Agency of Clinical Innovation Disability Network*

#### Introduction

By definition a person with an intellectual disability is less likely to be able to fulfil normal social roles. Their disabilities are likely to disadvantage their access to health services on the basis of limitations of communication skills, problem solving skills and health literacy. However, health services rely on clients identifying a health need and asking for a service. This combination clearly contributes to the recognised problems that people with an intellectual disability have in establishing equity of access for their health needs. The NSW Health system is complex. Frequently people with intellectual disability have special needs that need to be taken into account when providing a service. There is a critical role for a parent, relative, carer, advocate or disability professional (referred to as advocate) to enable a person with intellectual disability to have equity of access. This document, while recognising the primacy of the rights of the individual with disability, outlines the roles that an advocate can have, or needs to have, to enable appropriate equity of access to the NSW Health system and what to do in situations where the service is felt to be inadequate. This involves enabling accurate history taking and communication, understanding the pathways to care and the avenues for review.

#### The importance of the History, Past Reports, Current Medications and Asking Helpful Questions.

80% of the information needed for a diagnosis relies on an accurate history. A person with an intellectual disability may not be able to provide this for themselves. An advocate should aim to bring the history of their client to every consultation including the details of the presenting problem, history of previous health problems, history of early life experience, history of family background, current family contact, family history of physical, developmental and psychiatric problems, a history of past physical and mental problems, accurate account of current medications, doses, times, benefits and any side effects since

each medication was started. Information on previous medications, their benefits and side effects; detailed observation on the functioning of their client and any changes. It is a helpful routine to bring copies of other correspondence from other agencies and disciplines, their assessments and interventions. A doctor cannot provide comprehensive assessment and intervention without access to this information. It can be especially helpful to have questions that need addressing written down. Frequently a diary of recent pertinent events is also helpful to make objective the degree of a problem and any associated relevant events.

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**“There is a critical role for an advocate to enable a person with ID to have equity of access...”**

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#### The role of questionnaires.

In the context of time-limited access to a health clinician, it may be helpful for an advocate to access one of a number of questionnaires to facilitate the review of health issues. There are a range of questionnaires that may be helpful to ensure a routine health assessment or review is comprehensive. Access to a **CHAP** (Comprehensive Health Assessment Programme) ([www.adhc.nsw.gov.au/\\_\\_data/assets/file/0019/228106/Health\\_Care\\_Policy\\_Att\\_12\\_CHAP\\_brochure.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0019/228106/Health_Care_Policy_Att_12_CHAP_brochure.pdf)). The Centre for Disability Health has a range of useful documents to facilitate record keeping and communication with a health clinician. The **Personal Health Record for People with Developmental Disability**, **Pre-assessment questionnaire**, and **Depression Checklist** may be helpful in ensuring a full range of ques-

tions and health issues are considered ([www.cddh.monash.org/under Products and Resources](http://www.cddh.monash.org/under Products and Resources)). An instrument such as the **Developmental Behaviour Checklist** ([www.med.monash.edu.au/spppm/research/devpsych/dbc.html](http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html)) can be useful to summarise a range of emotional behavioural problems or the Depression in Children or Adults with Intellectual Disability Checklist for carers.

Access to the specialist/hospital or private health system is usually through a review by a General Practitioner (GP). It is recommended that everyone with an intellectual disability has at minimum an annual check-up and there is a Medicare rebate for an extended review to enable an annual health assessment. (There are now four Medicare Benefits Schedule items for health assessments based on how long the assessment takes (items 701, 703, 705 & 707, [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)).

#### How to ensure a satisfactory service provision

Good quality health service provision depends on the knowledge and skills of the clinician, the quality of communication between the patient and the clinician, and the level of trust between the clinician and the patient and, therefore the confidence in the relationship. Having a clinician that you respect and hold in high regard is the first element in receiving a good service. There is a certain element of choice in the health systems to be explored if the patient feels that service has not been to their expectations. Much of the value of a GP develops over developing a longer term relationship. It is therefore important to have a GP with whom you get on. The first approach to dealing with an unsatisfactory patient/clinician relationship is to find an alternative clinician to give an opinion or merely to give a second opinion, to enable greater confidence in the first. The first stage of course is to come prepared to your clini-



cian with specific questions you would like answered. It is helpful to ask for a copy of the clinician's report so that the discussion is documented. It is always reasonable to question advice. It is important to ask about the limitations of any advice and the risks of success and failure, and benefits of treatments and side effects.

### Escalation of concern when worried about the quality of service and advice

The quality of a service depends upon the level of trust and communication described above, and the vast majority of patients trust their clinicians and respect and value the advice given. Occasionally a patient may feel poorly treated or that they have received an unsatisfactory service. There are ways of responding to this constructively. As described above the first is to speak to have a meeting with the clinician to raise concerns and questions. If this is not sufficient it is quite reasonable to seek a second opinion, preferably with the support of the first clinician. In the hospital service the

next stage may be to talk to another member of the professional team such as a nurse or social worker. Hospitals also have a patient's advocate or patient's friend as a service to help patients or their families enquire about the processes of health provision and look for better solutions.

### Complaint processes

Should such systems of further enquiry or advice not provide resolution, there are formal complaint processes. One can write to the hospital through the Chief Executive or concerning a GP to the Division of General Practice for the location. It is possible to ask for copies of the medical records under Freedom of Information legislation and the process can be followed according to the NSW health website.

If it is felt that the professional has been negligent or harmful it is possible to make a complaint to the Health Care Complaints Commission. If there has been a failure to provide a service on the

basis of discrimination due to intellectual disability it is possible to seek advice from the Disability Discrimination Commissioner ([www.hreoc.gov.au/about/president\\_commissioners/innes.html](http://www.hreoc.gov.au/about/president_commissioners/innes.html)).

### In conclusion

The health system is a complex industry and getting the best from its service involves understanding the service structure as described in the Health Services for People with Intellectual Disability (see "Better Health Services for People with Intellectual Disability in NSW: The Agency of Clinical Innovation Disability Network" in this edition). There are ways of ensuring that you get the optimum use and benefit of that service through enabling quality communication. There are ways of asserting your concerns to enable a review of the service provided and if necessary formal ways of registering your dissatisfaction. ●

Comments on this document to the editor would be welcomed  
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## promoting resilience...

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Late last year I attended the "CHERI conference" Promoting Resilience 'Stacking the odds in kids' Favour' 6-7 September 2012. I listened intently with my intellectual disability filter.

Dr Sam Goldstein, neuropsychologist, author and educator from the USA noted there is no one definition of resilience and that it is more than bouncing back from a positive adaptation in the context of past or present adversity. Dr Goldstein 's interest in resilience began after his past child patients' were returning to him as adults with their own children. Those that he thought would be troubled were fine and those who he thought would be fine were troubled. He theorised that good coping skills were the key. Dr Goldstein then outlined that resilience is predicted by three factors 1. within the child, 2. within the family, and 3. in the community.

Resilience factors for youth with a Learning Disability:

- Temperamental qualities that allow the individual to elicit positive responses from others.
- Special skills and talents and the motivation to use them to an advantage in life.

- Nurturing caregivers providing structure, rules, and security.
- Supportive adults who foster trust.
- Openings or opportunities at a major life transition.

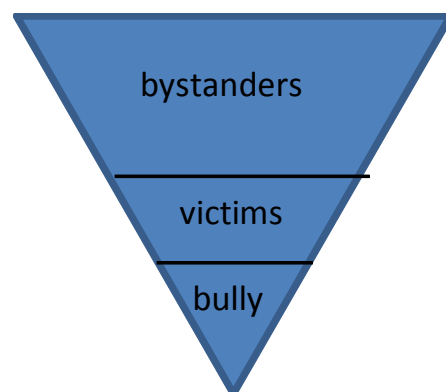
Five strategies to foster a resilient mindset:

- Teach empathy by practicing empathy.
- Teach responsibility by encouraging contributions.
- Teach decision making and problem solving skills that foster self-discipline.
- Offer encouragement and positive feedback.
- Help children deal with mistakes.

A/Prof Vijaya Mani Cavasagar from the Black Dog Institute discussed three processes leading to resilience. Coping was the first immediate process, adapting was the second medium term process and that resilience was the third long term process. She commented that mental illness occurred when an individual slipped between the cracks of coping and adaptation.

### Bullying

A/Prof Marilyn Campbell then discussed bullying and "Do students who have been bullied need resilience training?". In Australia 30% of students report being bullied and 50% cyber bullied. She commented that most victims are vulnerable and include students with an Autism Spectrum Disorder, a disability, gay, lesbi-



an, bisexual and transgender (GLBT) or those who suffered from anxiety - generally children who are different. A/Prof Campbell highlighted that bullying is deeply embedded in society and to only train the victim in resilience skills fails to acknowledge the dyadic relationship between the victim, bully and bystanders. Her first approach is to focus on the majority of the population who are the bystanders. She suggested that many bullies cannot be taught certain skills, such as empathy after the age of about 8 years of age, and that whilst training the victim after an event sends a message that they are the ones with the problem.

She suggests that bystanders be taught to walk away or leave chat rooms, text or email the student who was bullied afterwards, report the bullying anonymously, ostracise the bully and to defend the victim. A/Prof Campbell suggested to use motivational interviewing with the bully