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).

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 schoollink@chw.edu.au

promoting resilience...

Jodie Caruana
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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.

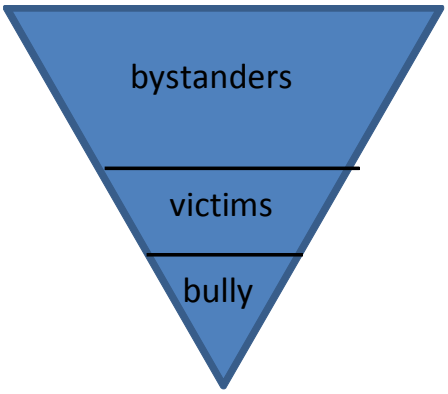
Five strategies to foster a resilient mindset:

- 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, lesbian, 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 bully's 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

and to ask the bullied "how do you want me to help you?".

Other Research

The conference motivated me to explore more about the resilience of people with intellectual disabilities. When searching the internet and other academic databases there was an obvious lack of material on the children themselves. Mothers were a common focus concerning children with disabilities and although the parents levels of coping and resilience are most important, it only composes one third of Goldstein's predictors of a child's resilience.

The main research article focusing on children and young people identified was by O'Sullivan, Webber and O'Connor in 2006. Through interviewing young people with an intellectual disability, their carers and other supports they identified three strategies to promote resilience:

1. Teaching young people social skills and more age appropriate behaviours
2. Structuring the environment
3. Removing the young person from triggers of challenging behaviour

The focus was on pre-empting possible problems rather than only teaching coping strategies as often the nature of their disability results in rigid and inflexible behaviours. O'Sullivan et al also highlighted the need for community awareness of the diverse behaviours that people with an intellectual disability exhibit to prevent criticism and vilification by strangers and exclusion in community activities.

In Summary the principles of resilience are similar for typically developing young people and those with intellectual disabilities, including factors within the individual, family and community. With young people with an intellectual disability it is especially important to accept aspects of the child's temperament influenced by their disability that cannot be changed, to create environments for success and self-confidence and to educate the community in the diversity of behaviour. More research needs to be undertaken on the resilience of children with intellectual disabilities.

References

O'Sullivan, J.L., Webber, L.S. and O'Connor (2006) Young People with an intellectual Disability: Risk and Resilience. In

Katsikitis, M. (Ed) Proceedings of the 2006 Joint Conference of the APS and NZPsS 26 – 30 September 2006, Auckland, NZ: Psychology Bridging the Tasman: Science, Culture and Practice. The Australian Psychological Society Ltd.

Resilience Resources

- Presentations from the Promoting Resilience: Stacking the Odds in Kids' Favour can be accessed here: http://www.cheri.com.au/PromotingResilienceStackingtheOddsinKidsFavour.htm.
- Headstrong a curriculum resource on mood disorders, mental health and resilience available by the Black Dog Institute on www.blackdoginstitute.org.au
- Biteback an online program to help develop skills in resilience and promote overall wellbeing in typically developing 12-18 year olds www.biteback.org.au.
- Journal of Intellectual Disability Research special edition on resilience and parents of children with an intellectual disability Volume 53 part 12 pp 955–956 December 2009.
- Emotion Based Social Skills Training for children with Autism and Intellectual Disabilities www.ebsst.com.au

Resilience starts with accepting what you can and cannot change.

- Headstrong resource

Have you been to a conference, read a book or visited a website that you loved? Send us an overview to: schoollink@health.nsw.gov.au

The beautiful artworks in this newsletter are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at www.artsunit.nsw.edu.au

A sincere thankyou to all children and adults involved in the production of these artworks and this newsletter.
Remember; **Think Kids**

contact us...

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