



Council for
Intellectual Disability

Australian Senate

Community Affairs Reference Committee

Via Committee Secretariat

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September 9, 2015

Dear Committee Members,

I am providing additional evidence as requested by the Committee at my appearance at the Sydney hearing for 'Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings' on August 26, 2015.

Evidence is provided below on the following areas:

- Supports for family members of people with a disability
- Active Support – training for support workers

Supports for family members of people with an intellectual disability

As a prevention strategy we have suggested that family members of people with an intellectual disability have access to family support from diagnosis and into young adulthood.

NSW CID engages with numerous families through our work, especially with our state-wide information service. People have repeatedly told us that they would appreciate having a trusted source to access when then needed support. Preferably this would be a place that they can return to time and time again, but not have to 'start from scratch' with their story each time. It would be particularly valuable to have an established relationship at a time of transition or crisis.

Family support could include, but is not limited to:

- Support and education so that positive and high expectations are developed for their child
- Enhancement of confidence and skills to advocate for their child
- Providing forums for both professional and peer support
- Information about current and best practice in relation to areas such as therapy, education and health care
- Assistance to develop problem solving skills
- Access to professional support such as psychology
- Support to maintain personal, family and social relationships

Strengthening the family is linked to better outcomes for children. A family member recently told NSW CID, it should be “whatever our family needs to function the best we can so we can support our child”.

Currently there are a range of initiatives provided across Australia and NSW CIDs observation is that they are fragmented and offered through a variety of sources. Many operate on project funding, have limited time frames and are not able to meet the demand.

Examples of programs include:

Resourcing Families NSW

<http://www.resourcingfamilies.org.au/>

Stepping Stones – Triple P for parents of Children w Special Needs

<http://www.triplep-steppingstones.net/au-en/home/>

Parent to Parent QLD

<http://www.parent2parentqld.org.au/>

Positive Partnerships – Australia wide

<http://www.positivepartnerships.com.au/>

Association for Children with a Disability – Victoria

<http://acd.org.au/support-local-area/>

Carers Australia

<http://www.carersaustralia.com.au/>

Other various associations that may be based on a specific disability such as Down Syndrome organisations. These provide a range of support, information and advice for parents

Many early intervention services also offer additional support for families, but this is not funded as part of an individual's package. It is often conducted in addition to funded work at the cost of the organisation. It is however done as early childhood educators are acutely aware of the benefits in working with the whole family.

Resourcing or block funding these services in the future may be necessary as people are not always aware of the benefits of participating in such a program until they have experienced it firsthand. Also outreach work may be needed to connect with families before they are aware of a service or of the possibilities it offers.

Active Support – training for support workers

There is evidence available that indicates a different approach to training of support staff can lead to much better quality of life outcomes for people with an intellectual disability both within supported accommodation settings but also and importantly in the broader community.

Person Centred Active Support is an evidence-based approach to supporting people with intellectual disabilities.

“Active support focuses on enabling people with intellectual disabilities to make the most of the opportunities available to them at home and in the community, so that people spend their time engaged in meaningful activities and relationships, growing in skills and independence, experiencing choice and control, and being seen as valued members of their community, irrespective of the degree of intellectual disabilities or the presence of additional difficulties such as autism or challenging behaviour.” (Ockenden et al p 99)

This is a much more facilitative and empowering approach to support to the traditional type of training offered in the community sector and is aligned to the broader goals of the National Disability Insurance Scheme.

These next pages include brief descriptions of journal articles and information that have been provided as attachments.

Flyer - Active Support

“Every Moment Has Potential” is an online learning resource that introduces Disability Support Workers to the Four Essentials of Person Centred Active Support and starts them on the road to putting these ideas into practice.

Flyer - Supporting Inclusion Training

'Supporting Inclusion' is an online learning program that is based on the principles of person centred active support, and is focused primarily on how this framework can be applied not just within supported accommodation services, but also out in the community.

The online learning program has been developed to create a space where disability support workers can think about what social inclusion means for people with intellectual disability, and learn or refresh some useful tools and strategies to support people with intellectual disability in ways that will promote their social inclusion.

Journal Articles

Active Support – Fundamental to Positive Behaviour Support

John Ockenden, Bev Ashman & Julie Beadle-Brown (2014)
Research and Practice in Intellectual & Developmental Disabilities, 1:2, 98-107

“Implementing active support not only provides conditions in which challenging behaviour is likely to decrease, thereby reducing the need for the implementation of positive behaviour support, but, where such implementation is necessary, it can provide a valuable foundation upon which positive behaviour support can be built.” p 98

Mediating Community Participation: Practice of Support Workers in Initiating, Facilitating or Disrupting Encounters between People with and without Intellectual Disability

Bigby, C & Wiesel, I (2015) Journal of Applied Research in Intellectual Disabilities 2015, 28, 307–318

“Seldom do training materials bring into focus the roles of support workers in reassuring, educating or interpreting behaviour for strangers that facilitate encounters and, which in the longer term, may add to the confidence community members in interacting with people with intellectual disability” p 9

“She's been involved in everything as far as I can see”: Supporting the active participation of people with intellectual disability in community groups”.

Diane Craig & Christine Bigby (2014) Journal of Intellectual and Developmental Disability

“The study identified a number of interventions and ways of approaching community groups that have the potential to increase the extent to which people with moderate levels of impairment become active participants” p1

“This study has shown that participation for those with moderate levels of impairment is a very real possibility as long as community groups are given specialised support, information about intellectual disability, and efforts are made to foster a particular set of contact conditions.” p13

Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework

Christine Bigby, Marie Knox, Julie Beadle-Brown, and Emma Bould
Intellectual and Developmental Disability 2014, Vol. 52, No. 5, 348–366

“Provision by staff of facilitative assistance, an approach known as “active support” or “person-centered active support,” has been shown to increase quality of staff support and levels of engagement of people with severe levels of intellectual disability, effectively compensating for the disadvantages of a high level of impairment”. p 349

It is concluded that if people with disability are to benefit from the current major disability policy reforms “significantly more attention must be given to observing and improving the quality of staff practices and ensuring more of these are good.” p 364

Please contact me should you require any further information.

NSW CID looks forward to receiving the final report and recommendations.

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