Symposium Report:

Realising the Hopes and Dreams of Parents with an Intellectual Disability 19th and 20th November 2012

Policy recommendations in the areas of:

Family Support

Child Protection

Disability Services

Presented by the

BOLD Network & Queensland University of Technology School of Public Health and Social Work

QUT

Bold
Better Outcomes for Parents with Learning Disabilities

Realising the Hopes and Dreams of Parents with Intellectual Disability Symposium

Parents with Intellectual Disability are estimated to be 1-2% (ABS, 2000, McConnell, Llewellyn and Ferronato, 2000) of the parenting population and are believed to be a group growing in Australia. Whilst there is currently no specific measure of the number of Australian families headed by a parent with an intellectual disability, the best available estimates are that 1-2 per cent of Australian families with children aged 0-17 include a parent with an intellectual disability (Lamont and Bromfield 2009). Based on this measurement, the BOLD network estimates that there may be between a minimum 30,000 and maximum 70-80,000 children with a parent with an intellectual disability in Australia today and between 5,240 to 12,000 children with a parent with an Intellectual Disability in Queensland. Wade et al, estimated in Australia there are around 40,000 children being raised by a parent or parents with intellectual disability (McConnell, Llewellyn, Matthews, Hindmarsh, Mildon & Wade, 2006). The reality is though that many mothers and fathers fly under the radar of services. These mothers and fathers have been referred in research as the hidden population who are parents who do not want to be labelled as having intellectual disability or learning difficulties. They want to pass in the community as being just like any other parent (Llewellyn, 2012, personal communication).

Research in New South Wales and Victoria has shown that parents with intellectual disability are over-represented in child protection services and legal proceedings (Booth, Booth, & McConnell, 2005; McConnell, Llewellyn, & Ferronato, 2000; Lamont and Bromfield 2009; Swain et al 2002). The Intellectual Disability Rights Service in New South Wales estimates that 10% of children in care systems are children of parents with intellectual disabilities (IDRS, 2012). International research (Booth, 2002) shows rates for the removal of children varying from study to study and country to country in a range between 30% to 80%. In the UK, the evidence suggests that 40%-60% of children are taken into alternative care. Parents with intellectual disabilities in the US and UK have been found to be 15 to 50 times more likely than other parents to have their children removed and placed in care, this is rarely because of allegations of abuse and mostly due increased risk of harm due to neglect (Bigby, Fyffe & Ozanne 2007, McConnell & Llewellyn 2002). Some of the reasons why parents with intellectual disabilities may be over-represented include living conditions (eg. poverty, unemployment); the role of prejudices beliefs, perceptions and expectations (McConnell et al 2000); existing co-morbid conditions such as psychiatric illness (McConnell & Llewellyn, 2002); and the significant gaps in support services (Booth, 2000).

What is currently observed in Queensland is children being removed from parents with Intellectual Disabilities who are willing to parent but require some support to parent well and effectively. These supports are often not forthcoming at prevention and early intervention stage and ultimately there is a tertiary services response which results in children being removed and then placed in the alternative care system. Research shows that parents with intellectual disability can successfully parent if supported appropriately for instance through varying shared parenting arrangements with family or other significant people and/or service supports. For instance there have been several programs developed and tools for parenting support programs that assist parents with intellectual/ cognitive disabilities by the Healthy Start Parenting Research Centre, based at the Sydney University (http://www.healthystart.net.au/) and some work being done by the Intellectual Disability Rights Centre (Dr Margaret Spencer's the UPS program – Understanding and Planning Support Planning for

People with Learning Disabilities program) and the Council for People with Intellectual Disability in New South Wales.

The **BOLD/QUT Symposium 'Realising the Hopes and Dreams of Parents with Intellectual Disabilities'** was held on the 19th and 20th of November 2012 and was attended by a range of health and welfare professionals as well as parents with intellectual disabilities. The Symposium organisers resolved to present the recommendations to your department for consideration and to the Child Safety Review.

The following recommendations before you are underpinned by:

- The recognition that most parents with intellectual/cognitive disabilities want to be good parents.
- The recognition that their efforts to be good parents is being compromised by their lack of support.
- The recognition that a Child Safety system which provides support to children once they are removed from their parents and support to their 'out of home care' rather than to the children in the care of their natural supports is an improperly inverted system - a system where resources are focused on the tertiary end of the system rather than the prevention and early intervention system ends.
- The belief that if resources are transferred from the tertiary end to directly supporting parents with Intellectual Disability, they are more likely to succeed as parents.
- The United Nations Convention on the Rights for People with Disabilities 2006, in particular Article 23.2 ..Where it is agreed "State Parties shall render appropriate assistance to persons with disabilities into the performance of their child- rearing responsibilities".

Recommendations from the Symposium:

Whole of Government

1. The state and federal governments to develop new legislation that places at its centre the United Nations Convention on Rights for People with Disabilities and principles of inclusion, self-determination and valuing of people with disabilities in our society – a **People with Disabilities Act.**

2. The UN Convention on the Rights of Persons with Disabilities Article 23.2 states that:

'...States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities'. The Symposium endorses the above statement and requests:

  - Queensland state government departments – Department of Health, Education and Communities - through policy formation and practice recognise the people with intellectual/cognitive disability have reproductive and parenting rights as well as sexual rights, and provide adequate support so children of these parents are able to stay with their natural family.

3. Improvement of Workforce Quality through:
  - Department of Communities specifically fund services to provide appropriate training and supervision for their staff, rather than the cost coming out of individual funding packages and/or block funding which should really go to providing support hours for clients.

- Training and supervision of staff, and networking and service collaboration hours should be included and counted as outputs under current service agreements as part of a staff member's casework hours, as these all go towards improving the service for the client, capacity and retention of staff. This will motivate services to provide appropriate training and supervision hours to its staff.
- Government and Non-government organisations collaborate to facilitate improved methods of recruitment and training of support staff who work with people with disabilities ensuring that people's rights according to the United Nations Convention on Rights for People with Disabilities and principles of social inclusion, self-determination and value and contribution to community are supported and facilitated by organisations providing support to people with disabilities.

4. For families where one or both parents have intellectual disability to receive the support they require, cross-sectorial collaboration and ownership is imperative.
    - The Director General of the Department of Communities needs to establish a consultative committee with representatives from Communities, Child Safety and Disability Services to develop a memorandum of understanding and action plan outlining how the three agency will work together to support families where a parent or parents have disabilities.
    - Services and agencies from these sectors also need to be supported in their service agreements (for example the service objectives and output categories) to work together to take ownership and responsibility for achieving successful outcomes for individual cases, rather than operating in sector silos.

Disability and Community Care Services Workshop Responses:

5. Disability and Community Care Services Queensland improve their policy response in providing appropriate resources to support parenting for people with intellectual/cognitive disabilities according to the United Nations Convention on the Rights of People for People with Disabilities by:
    - Improved access for parents with intellectual disability, to access funded packages to enable them resources to support their parenting of child/children. Parenting roles and responsibilities are not generally included under the eligibility criteria and various assessment tools used by the Department.
    - The requirements on use of funded packages should be flexible enough to provide support to children as well as the parents. These packages must take into account that parent's needs change as children go through different developmental stages.
    - Increased number, funding and resources towards services by the Queensland government, such as Alina, that provide specialised support for parents with intellectual/cognitive disabilities in becoming more effective parents.

6. The UN Convention on the Rights of Persons with Disabilities Article 23.2 states that:

'...States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities'. The Symposium endorses the above statement and requests:

- Queensland Government represent to the National Disability Insurance Scheme Implementation body that that the NDIS recognise that support to parents with an intellectual disability is a 'reasonable and necessary support' under the NDIS and is eligible for funding.

7. Young People Transitioning from Out of Home Care at age 18
    - Disability and Community Care Services review its eligibility criteria and assessment tools for young people with intellectual/cognitive disabilities to receive Disability support who are exiting the Child Safety system, in order to improve transition for this group into adulthood and live successfully and have a meaningful quality of life in the community.
    - Disability and Community Care Services provide young people with intellectual/cognitive disability, as part of their transition planning process, provide funded support to these young people with intellectual/cognitive disabilities once they turn 18, instead of them being abandoned out into the community when they turn 18. This will lessen the likelihood of early parenthood, homelessness and entering exploitative relationships and facilitate further education, potential employment or valued roles and meaningful and positive relationships.

8. Improved Advocacy
    - For families where one or both parents have intellectual disability, the number of independent advocacy services be increased and/or further funded by state government to provide these families support in having their voice heard in negotiating and managing their parenting responsibilities with Child Protection, disability services, education systems, legal aid and community legal services and other mainstream support services such as housing and Centrelink.' The current number and funding for advocacy services in Queensland for people with disabilities is alarmingly low and should be increased to support people to voice their rights under the UNCRPD.

Family Intervention Workshop Responses:

9. The UN Convention on the Rights of Persons with Disabilities Article 23.2 states that:

'...States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities'. The Symposium endorses the above statement and requests:

- That early intervention services such as pre-birth parenting programs and child health support, and specialised services such as Alina Service become the norm as opposed to being the only service in Queensland providing this specialized response.

10. Improve accessibility to service provision from Family Support Services through:
    - Provisions within service agreements for flexibility in their entry and exit requirements, relaxing time and taking referral restrictions and being able to meet intermittent or long-term support needs.
    - Requirements by funding bodies (Department of Communities) to provide more in-home flexible support based on the parent's needs to develop skills around parenting as opposed to making the parent fit the model the service provides. For example receiving and practicing parenting education and skills in-home, and/or require outreach or transport assistance for parent and child.'

- Their workers being trained in and required to utilize evidence-based educational strategies and programs that work with parents with intellectual/cognitive disabilities and other groups with particular needs.

11. The Department of Communities acknowledge through policy and practice the rights for people with Intellectual/cognitive disabilities under *United Nations Convention on the Rights for People With Disabilities 2006* that people with disabilities have sexual, reproductive and parenting rights. Responses would include:
    - Within Disability and/or mainstream service provision, Family and Lifelong Planning for a person with disability must encompass parenting goals and responsibilities, (not simply sex education).
    - Ensuring young people with disabilities are *consistently* educated using evidence-based strategies regarding their family planning options, and dealing with relationships such as the Department of Communities providing funding for Family Planning Queensland to deliver (already developed) training packages to families, teachers and workers who support people with intellectual disabilities to learn about sex and relationship education and contraception; and to develop training packages for youth workers and disability workers who are working with young people and adults with intellectual disability to support people with intellectual/cognitive disabilities around pathways to parenthood and family planning for adults with intellectual disability.

12. Mainstream parenting programs should improve their access and response to parents with intellectual/cognitive disabilities by:
    - Providing individualised, home-based and flexible (and not time limited) allowing for intermittent responses in order to provide support to parents with a wide variety of issues including parents with intellectual/cognitive disabilities.
    - Requirements that they train their workers in Parenting Programs which are more likely to work with parents with intellectual/cognitive disability and are based on evidence and research.
    - Maintaining data of its clients who have disability issues for government data collection requirements, such as are currently done with clients with ATSI or CALD backgrounds.

13. Shared Parenting models
    - Department of Communities to utilize existing research on Shared Parenting models to fund pilot programs in this area.

Child Protection System Workshop Responses:

14. The UN Convention on the Rights of Persons with Disabilities Article 23.2 states that:

'...States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities'. The Symposium endorses the above statement and requests:

- That a person's disability and therefore their 'capacity' not be used as a reason for child removal and all services involved in supporting parents in our state engage in early intervention supports as opposed to tertiary responses.

15. A whole of government approach to improving supports to families in our community is required and an overall commitment to system and worker transparency so that people and systems are held accountable to agreements and decisions that are made.

16. Within Child Safety, children and adults with intellectual/cognitive disabilities need to be seen as a priority area and not have their needs labelled simply as ‘complex’ needs.

17. There needs to be a commitment and action on moving resources from tertiary response to early intervention within Child Safety for all families with intellectual/cognitive disabilities.

18. There needs to greater collaboration between Child Protection, Disability Services and Parents with Intellectual/Cognitive disabilities
    - Where intellectual disability has been identified, a 'recognised entity' with expertise in intellectual disability is involved in case planning and supports. Where possible, this is done in consultation with the person with an intellectual disability.
    - There should be shared responsibility between Child Protection, Disability services and/or the non-government service over the life of the case, not siloed into different services.
    - A commitment to reunification in all cases and by all stakeholders.

19. Disability and Community Care Services eligibility :
    - Parents with intellectual disability are to have a separate eligibility criteria for funding and support due to the unique and ongoing demands of parenting across the lifespan.

20. Foster Families
    - Foster care system needs to shift focus from fostering individual children to "fostering families". Foster families should be encouraged to build relationships with natural parents in order to offer support to families as a whole rather than children in isolation and model good parenting to the natural parents, while allowing the relationship between parents and child to continue.

21. Workforce Quality Improvement
    - There should be a focus on improving workforce quality within Child Safety, for instance a priority to recruit staff with social work or social sciences university qualifications in order to improve individual worker response and practice approaches of Child Safety services.

22. United Nation’s Convention on the Rights of People with Disabilities – Article 2 *"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms-*
    - Flexible approaches are required in order to uphold the UN Convention that 'reasonable adjustments' are made to allow parents with ID to parent successfully. – in practice allowing more time for parents to participate and undertake parenting programs and make them more individualised and flexible; allowing more time for parents to meet requirements of Family Group Meetings; providing support to manage read, understand and manage documentation; and support to make more reasonable, flexible and individualised agreements between parents and Child Safety.

Future Plans:

The BOLD network and Queensland University of Technology is committed to continuing to advocate for systemic change in the Queensland government’s response to supporting families where one or more parents have an intellectual or cognitive disability. Disability and Community Care services, Child safety and Family support service responses have to be improved to an prevention/early intervention service response in order to support these families in our community. We all have a responsibility under the United Nations Convention on Rights for People with Disability to support these families in our community.

Attachment 1

United Nations Convention on the Rights for People with Disabilities (2006)

Article 6 - Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7 - Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 23 - Respect for Home and the Family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

    (*a*) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
    (*b*) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
    (*c*) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.
3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

References

Australian Bureau of Statistics (2000). Australian Social Trends 2000. Accessed October 25 2012, from www.abs.gov.au

Bigby C, Fyffe C & Ozanne E (2007). Planning and Support for People with Intellectual Disabilities: Issues for Case Managers and Other Professionals, Jessica Kingsley Publishers, London.

Booth T (2000). Parents with learning difficulties, child protection, and the courts. Representing Children, 13(3), 175–188.

Booth T.(2002) 'Parents with Intellectual Disabilities' published on http://www.intellectualdisability.info/families/parents-with-intellectual-disabilities. Accessed September 9, 2012.

Booth, T., Booth, W., & McConnell, D. (2005). Care proceedings and parents with learning difficulties: Comparative prevalence and outcomes in an English and Australian court sample*.* Child and Family Social Work*,* *10*, 353-360.

Intellectual Disability Rights Service (2012) BOLD/QUT Symposium keynote. See www.idrs.org.au,

Lamont, A. and L. Bromfield (2009). Parental intellectual disability and child protection: Key issues. NCPC Issues 31. Australian Institute of Family Studies. Melbourne.

McConnell D Llewellyn G & Ferronato L (2000). Parents with a disability and the NSW Children's Court. Lidcombe, NSW: University of Sydney, Family Support and Services Project.

McConnell D & Llewellyn G (2002) Stereotypes, parents with intellectual disability and child protection. Journal of Social Welfare and Family Law 24(3) 2002: 297–317.

McConnell, Llewellyn and Ferronato (2006) Context contingent decision-making in child protection practice. International Journal of Social Welfare, 15(3), 230-239.

McConnell, D., Llewellyn, G., Matthews, J., Hindmarsh, G., Mildon, R., & Wade, C. (2006). Healthy Start: A national strategy for children of parents with learning difficulties*.* Developing Practice: The Child, Youth and Family Work Journal, 16*,* 34-42.

Swain P Goodfellow J Lee J Cameron N & Bennett W (2002). Pride and Prejudice: A Snapshot of Parents with Disabilities' Experience of the Child Protection System in Victoria.

United Nations (2006) CONVENTION on the RIGHTS of PERSONS with DISABILITIES. Accessed on March 3 2012. http://www.un.org/disabilities/convention/conventionfull.shtml

REALISING THE HOPES AND DREAMS OF PARENTS WITH AN INTELLECTUAL DISABILITY

PROGRAM: Day One – Monday 19th November

8am: REGISTRATION DESK OPENS - Welcome tea and coffee served on arrival

WELCOME – Gardens Point, D Block, Room 101

8.40am	MC / Conference Chair Welcome	
8.45am	Welcome to Country Ceremony	
9.00am	Symposium Welcome & Introduction	Professor Robert Lonne

PLENARY 1 - Gardens Point, D Block, Room 101

9.10-9.30am	"Hopes & Dreams of Parents with an intellectual disability" **Alina – Anglicare Southern Queensland**
9.30-10am	**Kevin Cocks AM,** *Antidiscrimination Commissioner, Queensland*
10-10.30am	**Michael Hogan,** *Deputy Director-General, Dept of Communities, Child Safety and Disability Services*

10.30-11am	MORNING TEA

PLENARY 2 - Gardens Point, D Block, Room 101

11-11.45am	**Dr Margaret Spencer PhD,** *Intellectual Disability Rights Centre, Sydney* Designing family support services and systems to best meet the parenting "Hopes and Dreams" of parents with an intellectual disability
11.45am-12.30pm	**Lindsay Wegener**, *Chief Executive Officer, PeakCare* How child protection systems can better work with parents with an intellectual disability to achieve their parenting "Hopes and Dreams"

12.30 – 1.30pm	LUNCH

PLENARY 3 - Gardens Point, D Block, Room 101

1.45-2.35pm	**Professor Lesley Chenoweth**, *Head of Campus Logan, Deputy Vice Chancellor and Provost, Griffith University* How disability systems can best work with parents with an intellectual disability to achieve their parenting "Hopes and Dreams"
2.40-3.15pm	**Theresa Mace**, *Kummara Family Care Centre*
3.15-4.40pm	**PANEL SESSION** How family support, child protection and disability services systems can best work with parents with an intellectual disability to achieve their "Hopes and Dreams" as parents

REALISING THE HOPES AND DREAMS OF PARENTS WITH AN INTELLECTUAL DISABILITY

PROGRAM: DAY TWO – TUESDAY 20TH NOVEMBER

8.00am: REGISTRATION DESK OPENS - Welcome tea and coffee served on arrival

PLENARY 1 – Gardens Point, B Block, Room 117

8.45-9am	**Welcome**
9-9.30am	**Dr Jenni Mays and Dr Julie King,** *QUT School of Public Health and Social Work* Recognising difference: The social and cultural construction of (intellectual) disability
9.30-10am	**Dr Margaret Spencer – Video Presentation "We are a family"** UNCPRD Article 23 states: "Respect for Home and Family affirms the rights of people with disability to engage in intimate relationships, marry and have children". "We are family" explores what 'being a family' means to three families where one or both parents have intellectual disability. This video was made by the families in collaboration with Intellectual Disability Rights Services. Followed by a discussion

10-10.30am	MORNING TEA

10.35am-12.30pm **Concurrent Practice workshops: Best practice in working with parents in realising their "Hopes and Dreams"**

Stream 1 Room B121	Stream 2 Room B122	Stream 3 Room B124
Disability Services stream	***Child Protection stream***	***Family Support stream***
Presenters: **Alina Family** and **Morrie O'Connor** (CLA)	*Presenter:* **Ms Sue Gill** (Child Safety Service Centre, Dept of Communities, Child Safety and Disability Services)	*Presenter:* **Dr Margaret Spencer** (Intellectual Disability Rights Centre, Sydney)

12-1pm	LUNCH

1-2.30pm **Concurrent Policy workshops: Developing policy positions to achieve best practice in working with parents to achieve their "Hopes and Dreams"**

Stream 1 Room B121	Stream 2 Room B122	Stream 3 Room B124
Disability Services stream	***Child Protection stream***	***Family Support stream***
Facilitators: **Dr Jenni Mays** & **Dr Julie King** (QUT School of Public Health and Social Work)	*Facilitators*: **Lorraine Dupree** (PeakCare) & **Roberta Greimel** (PhD Candidate)	*Facilitators*: **Dr Margaret Spencer** (Intellectual Disability Rights Centre, Sydney) & **Julie Nelson** (Red Cross)

2.30-2.45 pm	BREAK

PLENARY 2 – Gardens Point, B Block, Room 117

2.45-4.45pm	**Panel discussion – comprising facilitators from workshops** Developing policy positions and advocating for how family support, child protection and disability services systems can best work with parents with an intellectual disability to achieve their hopes and dreams as parents
4.45-5pm	**Bringing it all together:** Facilitated by **Morrie O'Connor** Director Community Living Association