

## Powerful Parents Self Advocacy Group (PPSAG)



### Mission Statement and key initiatives as at May 2015

We are a group of parents with an intellectual disability who believe that most parents should be supported to have their children at home with them

The Powerful Parents Self Advocacy Group (PPSAG) is a sub-group of Reinforce, founded and led by Susan Arthur who herself is a parent with an Intellectual Disability who has had her child removed from her care.

PPSAG acts as both a support group and an agent of change particularly in regards to reinforcing United Nations Article 23 and the Australian government (as a signee) more strongly adhering to its principles.

United Nations Agreement Article 23 states that: Countries will provide support to disabled people to help bring up their children....Countries will make sure children are not taken away from their parents if they don't want to be, except when the law says it is the best interests of the child. This will not happen because of disability. (United Nations Enable Version of International Agreement on the Rights of Disabled People. Easy Read Version).

In March this year (2015) PPSAG ran a forum called "It Can happen If...Creating Positive Change for Parents with an Intellectual Disability"

PPSAG collaborated with other Health Services and Government agencies (including; OPA, Healthy Start, Department of Health and Human Services, Self-Advocacy Resource Unit and more); to open conversations for systemic change to current health practices in working with parents who have an intellectual disability.

Over 50 health professionals attended this day and over 90% of participants identified the need for 'lived experience' to be a part of training and education for health services who work with parents with an intellectual disability; in order to provide for the needs of the child & the whole family

The Powerful Parents Self Advocacy Group are very keen, given the right resources, to implement these services, training & education initiatives and continue to collaborate with health and other services.

#### Achievements of PPSAG to date

- Establish support and lobby group for parents with an Intellectual Disability
- Develop & produce awareness raising tools, such as; information on Reinforce website about PPSAG, PPSAG pamphlet and DVD “How Would You Feel”
- Liaise with influential stakeholders and establish partnerships Eg OPA, Healthy Start, DHHS, Sydney University etc
- Organise, present and run Forum “It Can happen If...Creating Positive Change for Parents with an Intellectual Disability”

#### Future Aims and Objectives

In essence PPSAG has identified a gross current lack in resources and information available to various Health and other services in working with and supporting parents with an intellectual disability. Resources and supports are deficient in valuable practical and lived experience components. During meetings between PPSAG, services commented on the value of this lived experience knowledge being shared. This group would like to develop a training package to be shared as both a community awareness raising and educational tool.

The aims of this would be to encourage conversations, awareness, co-operation, inclusion and support from various health services and the wider community. The other outcomes would be to breakdown existing negative attitudinal and organizational prejudices

The outcomes envisaged are to forge new practical supports of parents by services, more holistic understanding and pathways that are both inclusive and encourage self-determinism in decisions that directly impact on the lives of parents with an intellectual disability and their respective families. The ancillary outcome would be to promote self-esteem and social capital of Parents who have an intellectual disability whilst encouraging a sense of purpose and a channel for positive change out of adversity. The area of understanding the needs of Parents with an Intellectual disability is complex and multi-layered so consultation and collaboration would occur.

PPSAG has already developed some valuable partnerships and will continue to foster new ones and work with these individuals and organisations.

### PPSAG Projects at a Glance

- Continue to spread awareness and education of PPSAG through recruitment of new members and partners to the group
- Support parents with an Intellectual disability through peer support within PPSAG group
- Continue to alert and lobby government and health services about the changes needed to better support parents with an intellectual disability
- Nationwide connections, networking, discussions on a closed PPSAG Facebook page
- PPSAG would like to develop training materials for parents with an Intellectual Disability in Easy English
- PPSAG would like to develop a Training package for Health professionals
- PPSAG would like to create and produce another DVD to compliment “How would you Feel” in documentary style with conversations between Health Professionals and Parents with an Intellectual Disability to shift perceptions, create awareness and encourage positive changes health system & community changes that provide supports to and benefit the children and whole family.
- Organise and present at another Forum – Where to from here - practice in action-creating positive change for parents with an intellectual disability

***Professor Gwynnyth Llewellyn Sydney University: "When babies are taken away from their mothers early on and the mother doesn't really understand why, then you have the potential for very distressed mothers, parents and families."***

Professor Llewellyn is a well-known advocate, academic and researcher (based at Sydney University), for families who have a parent with an intellectual disability.

Gwynnyth was a keynote speaker at PPSAG's Forum in March "It Can happen If...Creating Positive Change for Parents with an Intellectual Disability"

The Powerful Parents Self Advocacy Group will continue to consult with Gwynnyth and in consideration of all the groups initiatives incorporate the most recent evidence based research.

Please refer to the Reinforce website for updates on PPSAG

[www.reinforce.org.au](http://www.reinforce.org.au)

