

# Positive Powerful Parents

## Report from the Hand In Hand Parent Meeting

Melbourne  
19 September 2018





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We have a disability,  
But we are all the same.  
Why are we not equal?

Why do you say we can't look after are children?  
We can if we have the same support like other parents  
We just have a different way of parenting.  
So give us a chance and we will show you we can.

Yes we have a disability,  
We are like all parents out there.  
We have a unique way of parenting our children  
so can you please treat as equal.

We want to be treated like other parents,  
And have the same rights as other parents.

*Poem by Hand In Hand Parent Meeting attendee*

## 1.0 Introduction

### From Positive Powerful Parents (PPP)

PPP would like to thank Catherine Wade from the Parenting Research Centre (PRC) for her support with this project. PPP would also like to thank Jenny Ellison, Lucie and Vishnu, staff at the Melbourne Multicultural Hub, staff at the Self Advocacy Resource Unit (SARU), Reinforce Inc. and all of the people who attended the Hand In Hand parent meeting.

This report shares our stories so that people know what is happening to parents with intellectual disability. It is a true reflection of parents' lived experiences. We want the community to know that parents with an intellectual disability can be good parents when they have the support they need.

When parents with intellectual disability come together we help each other and we try to change the way child protection sees us.

This report has been written for DHHS workers, NDIS workers, families, health workers, disability workers, advocates and anyone interested in the rights of parents with an intellectual disability.



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## **2.0 About *Positive Powerful Parents***

Positive Powerful Parents (PPP) is a self advocacy group run by and for parents with an intellectual disability.

PPP started because of the numbers of parents with an intellectual disability who do not get the support they need to keep their children.

PPP works to make sure that parents with an intellectual disability:

- Have the same rights as any other parent in the community and are not treated differently
- Receive the support, education, and resources they need to keep their children at home
- Have the same right to reunification with their children as any other parent and are provided with the support, education and resources to make this happen,
- Know they are not alone
- Are treated with respect, and
- Get the support and funding they need to have good levels of access to their children when they do not live together.

PPP are currently running the Hand In Hand project. Hand In Hand seeks to educate government and the community about the needs of families where a parent has an intellectual disability.

### 3.0 About the *Hand in Hand* parent meeting

The *Hand In Hand Parent Meeting* was held in Melbourne on the 19th of September 2018. This meeting aimed to capture the authentic voices of parents with intellectual disability about their experiences with the services and supports available to them to support their parenting.

The parents joined a whole group discussion about parenting, responding to a series of questions posed to them by members of the *Positive Powerful Parents Self-Advocacy Group*. Following the group discussion a song written by the group was performed by Jenny Ellison and attendees painted banners. Poems written by parents were also spoken during the day.

#### Description of attendees

Twenty-five people attended the *Hand In Hand Parent Meeting*. And some parents who couldn't make it to the meeting sent in responses to questions beforehand, so their voices could be heard too.

Most of these participants were parents (mainly mothers, but also fathers) with intellectual disability, and the rest were advocacy workers or other support workers.

All parents with intellectual disability who participated were members of different advocacy groups for parents with intellectual disability.

The parents had children of different ages, ranging from a couple with baby under 4 months, to a parent with a 20 year old son. Most had only one child, and three parents had four children each.

The parents were from different locations across the state, many from regional areas, and some from closer to Melbourne.

Some of the parents had custody of their children and had never had them removed from their care, others had never had custody of their children, having them removed from their care soon after birth. Many had supervised access visits with their children at either regular or irregular intervals.

Of the workers who were there, they were from different organisations across the state, including MPower, SARU, Family Inclusion Network, Parenting Research Centre and VALID.

## 4.0 Question One

### Are there any supports or services that have helped you as a parent?

The mothers and fathers who attended spoke about a range of supports and services that have helped them in their parenting.

A common support named was *Cradle to Kinder*, which in Victoria is an intensive ante and postnatal support service to provide long term family and early parenting support for vulnerable parents under the age of 25 and their children. The idea of *Cradle to Kinder* is that it starts during pregnancy and continues until the child reaches four years of age.

The views of parents about *Cradle to Kinder* were very positive. Many said their worker had been really helpful in supporting them in the early months and years of parenting.

One mother of a young child talked about her experiences with *Cradle to Kinder*:

'I was having trouble communicating with DHHS.  
The worker came along to any meeting I had with DHHS. Any meeting, she was there.  
She helped me get access to my son. She helped me find my own place.  
Helped me get him to kinder, appointments, go down street, even for a chat.'

Another mother talked about how *Cradle to Kinder* helped her to get her child into day care.

A number of parents talked about their concerns about being able to **meet their baby's need when they first went home from hospital** with their newborn.

One mother talked about how it would have been helpful to have more support in the first few days of parenting, especially when she went home from the hospital with her newborn. She suggested that a helpful idea might be to have a 'helper mum' to come home from the hospital with you.



## 4.0 Question One *continued*

Of the parents who provided responses before the Forum, a number of points were made about the early days of parenting, illuminating the concerns faced at this challenging time:

- *'I was not prepared for the birth – no birthing classes were offered.'*
- *'I was afraid I would forget I had a baby.'*
- *'I was sacred and excited at the same time.'*
- *'[I was concerned about] lack of sleep during pregnancy.'*
- *'I was afraid I would die from all the videos I had watched.'*
- *'I wasn't told how much it hurts.'*
- *'[I was concerned about the] first night at home without nurses – what if I didn't wake up to him.'*

These parents who provided responses before the Forum, named a range of services/support with whom they'd had positive experiences. These included the *Cradle to Kinder* program, *MPower*, *Centacare*, various parenting and family support programs and early parenting centres.

One parent at the Forum talked about how she felt issues from her own past had not been properly addressed, and that this caused some distress during her pregnancy and early parenting of her child, because it raised feelings in her about her own experiences in foster care that she hadn't dealt with properly. This mother was now getting counselling with the local hospital to help her:

'I was an emotional wreck.  
I was finding parenting a lot harder than I expected, maybe because of my history in foster care?  
Haven't dealt with my own past. When I got pregnant it came up.'

A mother discussed her positive experiences with *Baptcare* after the birth of her baby, who she credited with helping her to keep custody of her youngest child:

'I found it really, really difficult. It was hard to trust people to come in and help me.  
*Baptcare* are still involved for another two months. They provided transport to places ...  
like [early parenting centres] and helped me get stuff for the house like baby gates.'

## 4.0 Question One *continued*

Another mother talked about some of the useful inform she learned from residential program at an early parenting centre:

'...some of the stuff I already knew [from parenting my older children], but I learnt a lot of new stuff too with my youngest.'

A mother with a new baby told of her recent experiences with her baby who was crying a lot. She and her partner took him to the Paediatrician and they found out the baby was under the recommended weight for his age. The parents saw this as a problem and were keen to do something about it quickly – they were relieved when they found out what the underlying cause of the crying might be.

The baby was admitted to hospital for two days to observe his weight as the hospital worked with mum and dad to find a good solution to his feeding. He wasn't getting enough milk from breast-feeding, even though his mum was trying really hard to make it work. They tried a combination of breast and bottle feeding and eventually everyone agreed that bottle feeding would be the way to go. The infant is now exclusively bottle-fed and there have been no further concerns about his weight.

Some parents talked about their experiences of the support system during the time they were going through ***child protection and custody proceedings*** in the courts.

A worker talked about the experiences of father who couldn't be present, but was happy to share with the group that he found a regional DHHS outreach service to be helpful during the time he was going through court system regarding custody and access to his child. This service also had a men's group attached to that service. But that service is now closed.

Other parents present also told of their experiences going through the court system. One mother talked about the help she got from a family support agency who were '*very helpful throughout the court case*' and were important in helping this mother to '*be able to have my daughter in my full time care*'.

One mother talked about her positive experiences with VALID, who '*gave me information for the lawyers, and helped me with some of the stuff my child's dads was doing at the time*'.

## 4.0 Question One *continued*

Another mother described her positive experiences with a support worker:

'She was easy to understand. If I needed help she'd answer that.  
She would take me to lawyers if I needed legal advice.  
Got me into [an early parenting centre] - provided transport to get there. Paid for train tickets.  
Paid for a lot of things for me and my child over 3 and a half years.  
The amount of help and advice I've got from her... I can't put a number on it.'

One mother noted:

'When they first took my son away I asked what is wrong with my parenting.  
After 3 meetings of asking they finally said it was my intellectual disability.  
Well, it would have been good to know that earlier so I could work with my support person to  
know how to address that – get the right support to learn what I needed to know.'

There was some discussion about the **National Disability Insurance Scheme (NDIS)** and how it may be a useful way to get the right supports in place for a parent.

A worker who was based in a location where the NDIS has been in place already for a number of years noted that the NDIS can be a good way to ensure a parent has parenting supports that meet their needs. The key is to ensure a person's NDIS Support Plan is re-considered once a person becomes pregnant, to suit their upcoming parenting role. So, the priority may need to move from supporting that person to achieve desired education or employment outcomes to make their goals and subsequent support plans more parenting-focused; *'NDIS support workers can really help with this.'*

While one mother present reflected that *'I put my daughter in my plan, but it wasn't really taken up'* another mother had a more positive experience with the NDIS. In her case NDIS was able to be used to obtain support in the first week after her baby was born, in the form of a support person staying over night at the family's home to help the mother respond appropriately to the child's cries at night for feeding. Her worker described how *'when she came home from hospital Child Protection required she had active supports in place. With the NDIS we were able to use that funding to get 1:1 support that helped support mum to feed baby over night.'*

## 4.0 Question One *continued*

While one mother present reflected that *'I put my daughter in my plan, but it wasn't really taken up'* another mother had a more positive experience with the NDIS. In her case NDIS was able to be used to obtain support in the first week after her baby was born, in the form of a support person staying over night at the family's home to help the mother respond appropriately to the child's cries at night for feeding. Her worker described how *'when she came home from hospital Child Protection required she had active supports in place. With the NDIS we were able to use that funding to get 1:1 support that helped support mum to feed baby over night.'*

*'When a parent becomes pregnant you can ask for a review of your plan.  
When you are pre-planning you can ask for parenting skills development.'*

A broad range of supports are included in the types of things people with disability can put in their NDIS plans, and many of these can be tailored to parenting. Home help/cleaning, budgeting, yard maintenance, 1:1 support to access community (playgroups, shopping), active supports, cooking, life skills etc are all relevant areas to consider how a support plan can be adjusted to focus on parenting support needs.

This worker noted that the catch phrases of NDIS are *'To have an ordinary life'* and *'Choice and control'*, which speak to the right the person has to choose how they are supported to live independently in the community.

Funding exists (e.g. through ILC) for organisations to start delivering parenting programs that are best suited to parents with intellectual disability.

*'Once you know you're pregnant, change your plan.'*

## 5.0 Question Two

### In your opinion, have you proven anyone wrong about your parenting?

When asked if they felt they had proven anyone wrong about their parenting, many of the attending parents gave very firm and sometimes emotional responses about their experiences. Many of them reflected themes of family members being in doubt about their capacity to parent, and being quite negative about their prospects in being allowed to keep their child.

One mother recalled being told by someone in her family that she 'couldn't fall pregnant because of my intellectual disability, but I actually did'.

A mother with older children who were no longer in her care recalled:

'My Nan, when I fell pregnant with my first child... my own mum left me when I was a baby. My nan said 'you're going to be like your mum'. I proved her wrong. I had my older two until they were 9 and 8. So I proved them wrong.'

Other mothers reported:

'Three days after my son was born they took my son off me straight away. I've been tossed every hurdle they've thrown at me. My disability does not make it impossible for me to be a parent. DHHS gave in and let me have custody of my son.'

'DHHS said that I wouldn't be able to get my kids back. My ex-partner too. It took 10 years of fighting but I got them back.'

'My mum was putting me down, saying I'm dumb, stupid. DHHS took my older three children, I have my youngest one and I am parenting her.'

## 5.0 Question Two *continued*

There was a building sense of pride among participating parents, as more and more parents told a similar story of how in the face of doubt from others in their lives, their capacity being queried based on very little evidence of their likely ability to parent, rather based solely on the label of intellectual disability alone, but then being proud when they could demonstrate their ability to parent well.

When asked if they had any advice for other parents who might be going through these experiences of doubt and resultant child protection and court proceedings, many parents responded quickly with statements like: 'Never give up' and 'Stay strong'.



Artwork by Hand In Hand meeting attendee

## 6.0 Question Three

### What would you like to see change?

A common theme that emerged from the forum was that unborn notifications are a frequent occurrence for parents with intellectual disability, and that they often occur in the absence of any evidence of future likelihood to abuse or neglect a child, and in the absence of the offer of support to the parent to obtain legal support or professional support to prepare them for parenthood.

One worker noted:

‘When child protection receives an unborn notification they should link that person in with support straight away!’

One mother described her experience when her child was born:

‘When I had my oldest, DHHS came to the hospital not even 24hrs after he was born. I had to leave him in the nursery so I could go to court – two days after the birth... DHHS wanted to take him off me right there and then.’

In this case, the mother was aware that an unborn notification had been made, and she had been linked into legal aid for pre-birth conferencing. The lawyers gave her the court papers the day after her child was born, and she was in court the next day, while her baby was still in the hospital.

Parents and workers present at the forum were shocked that court proceedings had happened so quickly following the child’s birth, and expressed concern that the mother was required to leave the hospital and front a court potentially in a state of physical and emotional distress, as is common for mothers in days immediately following childbirth. Some also noted the disruption to the mother-infant bonding process at this crucial time.

## 6.0 Question Three *continued*

Discussion addressed how the **intellectual disability label** often put the parents under heightened scrutiny – some described it as being '*red flagged*'. A worker described how in conversations they'd had with DHHS staff, there had been talk of the 'triggers for getting involved', which included drugs, alcohol, disability and being Aboriginal.

Feedback included:

'People doing drugs are allowed to have their kids, but parents with intellectual disability are seen as higher risk than someone with a drug problem.  
What's wrong with the system?'

'So many assumptions are made about people's capacity to parent based solely on the label ID.'

Of the parents who provided responses before the Forum, a number of points were made about assumptions often made about parents with intellectual disability:

- '*One disability doesn't equal being no good at anything.*'
- '*We can still be good/great parents.*'
- '*Don't be judgemental.*'
- '*One person's disability is not a reflection of anyone else's disability.*'
- '*Judge each case on it's individual merits.*'
- '*Give them a chance.*'
- '*Give us the support we need.*'
- '*I didn't tell [the hospital staff that I had a disability] – I was afraid to.*'
- '*[They] hand you paperwork to read, but you can't understand it.*'
- '*I thought [the hospital staff] might think I was not capable to look after my baby.*'



## 6.0 Question Three *continued*

There was discussion about ***what should happen at the time of an unborn notification***. Workers advised parents to 'get advice straight away when you're aware of what's likely to happen.' One worker noted that Child Protection are meant to link people into NDIS, and that this is written into DHHS Child Protection guidelines, but often Child Protection workers don't know that.

One worker queried whether there was a need to create resources to make sure people know what their rights are. In response, another worker described a new resource from VALID 'Steps to Speaking Out'.

Another discussed how at Child Protection Intake there is a real opportunity for intake workers to identify that the parent has a disability, and for that to trigger action to get the parent the right supports.

One worker noted:

'It's typical for parents to be required to have an early parenting centre visit soon after birth, but because we are in a regional area they say there's a very long wait for this. We've had good success at getting the parent in by planning wraparound services to allow mother to take baby home with lots of local supports. The Magistrates are OK with this. But usually once DHHS become aware of this, they magically find a place in the early parenting centre straight away.'

Discussion progressed to talking about what parents with intellectual disability should do once a notification is made. The advice centred around ensuring the right supports were in place, and keeping a record of the claims made against them.

One worker described a service available in a regional area called the Women's Legal Service, which has been successfully used by parents with intellectual disability in their area to provide legal support for unborn notifications. This type of support was thought to be useful as a way of '*keeping the Department on their toes*' – Child Protection staff tend to '*watch their conduct*' when there are other professionals looking out for the parent's rights.

## 6.0 Question Three *continued*

When asked how they know what their rights are in relation to unborn notifications and parenting, some parents acknowledge that they don't know what their rights are.

'Some of us don't know our rights. We know after experience.  
After having had two children removed, I was aware.'

One mother talked about the UN Convention of the Rights of Persons with a Disability (CPRD):

'For my daughter, the pre-birth notification happened  
in the year the UN CPRD was signed and ratified by Australia.  
Otherwise I wasn't aware of my rights. I became aware of it later.  
In the court case the decision was to remove my daughter from my custody.  
My solicitor told them I could fight the decision.  
But I decided not to, for the sake of the child –  
she was becoming aware of what was going on.'

In this case, Child Protective Services didn't offer any supports to the mother after the notification, or to provide support to the parents in court.

One mother talked about the lack of communication with her at the time of an unborn notification about her daughter while she was in an early parenting centre:

'My mother in law was called into a meeting that I wasn't told about.  
Everyone almost assumed that I would fail before I had a chance.  
I could see the writing on the wall. I left [the early parenting centre] feeling it was hopeless.  
I waited two-plus weeks for DHHS to let us know what was happening.'

Some discussion focused on the false allegations that were made about parenting behaviours, that was used as evidence of future risk to the child.

## 6.0 Question Three *continued*

One mother described her experience of receiving an unborn notification when she was 6 months pregnant:

'I had split with my partner, DHHS said they'd make a pre-birth notification. Three days after the child was born we found out he had some heart problems [holes in the heart]... I was told I could leave hospital anytime, but my child had to stay in the ward. I would go to the hospital to visit him. Then I got a notice from Child Protection that said I'd shaken him to wake him up – it was not true. The same day I was told I have to go to [a country town] where I live to go to court. I was told I'm going to lose him for 2 months when he comes out of hospital.'

Other mothers described their experience while at an early parenting centre:

'I was at the [centre] with my daughter and husband – I wasn't coping, someone made a false report to Child Protection, and because of that my mum doesn't trust me with my daughter. I only saw her for 5 mins on her birthday. It really causes problems in families.'

'I didn't find out what was happening with DHHS until the hospital. They got a court order to make the hospital keep me there for two weeks. My son and I were not allowed to leave. DHHS didn't let me know of their plans until the following year. It would have been nice to know what was going on at the time.'

## 6.0 Question Three *continued*

Another example described was by a mother who had been sexually abused herself as a child, who was told there was *'a chance she will sexually abuse her children'* because of her childhood history.

A worker described an example of a father she'd supported who had made *'a funny remark'* during an access visit *'he looks like an alien today'*, commenting on a fancy dress outfit the child was wearing. Information about this was recorded in a report as evidence the father may have been using drugs at the time and possibly was experiencing hallucinations.

Workers present talked about the injustice that occurs when false allegations go into Child Protection reports, noting there is no mechanism for having that information removed; *'Otherwise that stays in their files for a long time and gets cut and pasted for a very long time.'*

A worker commented on the tendency for there to be many different Child Protection workers involved with a single family over the course of their investigation – *'there is no sense of holistic care.'*

A worker said:

*'I encourage my parents to keep a diary and write down what's said by Child Protection. And to always have support with them so someone else is there as a witness.'*

Other suggested changes in the support system focused on ***characteristics of the programs*** and other supports available to best support parents with intellectual disability.

For example, one worker discussed how there is a limited number of programs offered in the community that provide long-term support:

*'When you're at court and they say you need to attend parenting programs, those programs need to be long term, and there needs to be more spaces available. Tweddle and PASDS are short term. That's something I would like to see changed.'*

## 6.0 Question Three *continued*

One mother said:

'The government are saying they are willing to pay foster carers extra money – instead of this why can't they put that money into better supporting parents with ID?'

Of the parents who provided responses before the Forum, a number of points were made about how support should look for parents with intellectual disability:

- *'Let us know our rights.'*
- *'Put things in writing for us – using language we understand.'*
- *'Don't overload us with information – make it more simple.'*
- *'Offer us a support person/advocate.'*

Some parents and workers talked about the support needs of parents in the time immediately after the birth of a baby. Some agreed that hospital support should be given earlier and for longer, perhaps with follow-up support after the baby returns home.

A number of parents talked about their experiences with access visits to their children who were not in their custody.

Parent discussed the unfair treatment they felt they experienced in gaining access to their children once they had been removed from their care.

'The court order says I'm meant to see her every two weeks. Usually it's supervised. I can do maximum 15 minutes unsupervised with my phone switched on, in a safe place, etc

## 6.0 Question Three *continued*

The access this mother is allowed is conditional and brief. For others present, the experiences were commonly negative:

‘There should be more access rights to your kids. I have three who I don’t see much – 1 to 2 hour access visits once per month for two of them.’

‘My access was cancelled one time because my child wanted to know about the ‘facts of life’. When I started explaining them to her my access was cut off straight away. I should be able to explain what I like to my own child.’

‘Stop removing our children. My 10 year old is now at the stage where she picks and chooses when she sees me. We’re not given the chance to help her deal with the fact she has two parents with ID, and to help her deal with her feelings about that.’

‘Parents with intellectual disability should be able to get the right support they need in order to get their children back, but if not, they should be able to see their children as much as possible.’

‘When I lost my older two I had one access. The worker said I was quite capable of looking after my children, but I am still on supervised access. I have a friend who helps with supervision, not a worker. But I can’t have any time by myself. I can’t even teach my kids how to ride a bike without someone saying ‘you’re not quite right enough to teach your child to ride a bike’. Give that person a chance to look after their kids without someone telling them they can’t do it by themselves.’

## 6.0 Question Three *continued*

### **Keep Shining**

Let them judge us  
Let them misunderstand us.  
Let them gossip about us.  
Their opinions aren't your problem.  
You stay kind  
Committed to love and free  
In your authenticity  
No matter what they say or do.  
Don't you dare doubt your worth or  
The beauty of your truth.  
Just keep shining like you do.

*Poem by **Hand In Hand** Parent meeting attendee*

## 7.0 Question Four

### What are the good bits or strengths about being a parent with intellectual disability?

When asked about the positive side of parenting, parents present at the forum reflected on the diversity of parenting styles and positive aspects of the relationship with their children – even where access to them is limited.

‘When I do see my daughter I try to remain as positive as I can.  
I don’t hide my disability from her.  
When I am with her I just adore the time I have with her.’

Workers were also able to articulate the positives about parents with intellectual disability:

‘They love their children; they make really good decisions around the care of their children; they are very positive; they go above and beyond to do everything that Child Protection ask of them - sometimes they’re asked a lot.  
But they do everything they can to prove they can be a good parent.  
They care for their children day to day to show they can parent just like anybody else.’

‘When they play with children – parents with intellectual disability keep going and keep going until they reach that child or until they respond.  
They are much more patient than other parents.’



## 7.0 Question Four *continued*

One worker commented:

'... even if you don't have your children in your care permanently, you are always a parent, no one can ever take that away from you. No one can take that right away from you.'



*Art making at the Hand In Hand parent meeting*

## 8.0 Question Five

### Do you think it is helpful to meet with other parents with Intellectual Disability?

The Forum asked the question of attendees about whether get-togethers like this or like in self-advocacy groups were helpful for parents. Responses were overwhelmingly positive from parents:

'I find it helpful to meet other parents with intellectual disability because seeing other parents with ID tells us that we aren't they only ones being picked on by Child Protection.'

'I often felt like I was the only one being picked on. I didn't realise there were other parents with intellectual disability who had lost their children.  
It was good for me to see I'm not the only one.'

Workers also believed such opportunities for interaction were helpful:

'It provides a sense of connection - everyone's stories are different but it can help to find other parents going through similar situations as you.'

'Without PPP putting this topic on the agenda it wouldn't have happened.  
Connecting is a really valuable thing to do.'

'Definitely valuable to bring parents together. [Our] group support parents more broadly. Its' good to foster age appropriate friendships. Normalising something that's not a normal situation can benefit everybody. Good for children coming together.  
Like a playgroup in a family space. Mentoring.  
We also have a group for parents who don't have their children with them.'

'There's power in numbers – to have a voice you need to come together.'

## 9.0 Summary

The parents present shared a mix of positive reflections about being a parent, and less positive reflections about their exposure to concerns about their parenting capabilities

Pre-birth notifications were a common experience for many of the parents present. Pre-birth notifications often occurred despite no evidence of past or future child maltreatment concerns, with risk being determined in such cases solely based on the person having the label of intellectual disability. Furthermore, many of the parents appeared to have been offered no legal or parenting support at that time.

These experiences highlight the need for a review and refinement of processes around pre-birth notifications, particularly where a parent has intellectual disability or learning difficulties. Awareness raising about the rights of expecting women and their partners to receive support - through NDIS where possible, and more broadly – will assist future parents to prepare for parenthood.

Many of the parents who contributed to the forum spoke about not being well prepared for parenthood. It seems that for many, given the high frequency of pre-birth notifications among those present, that the pre-natal period presents a real opportunity to prepare 'parents-to-be' with the knowledge and skills that will help to prepare them for childbirth and for parenting. Indeed, some argued that the parents have a right to have access to these supports at this time.

Workers noted that child protection staff should be referring a parent with intellectual disability to NDIS - where the parent is eligible - at the time of the pre-birth notification so that support plans can be adjusted to build in goals and supports that will focus on parenting needs.

Parents with ID may not be aware of their rights in pregnancy and parenthood. Many gave examples that suggested they had not been advised of their rights to question decisions and to ask for evidence about what others claim they have or have not done.

There appears to be very little awareness among parents and professionals alike of the rights afforded to people with disability who choose to become parents. This is despite the CPRD being ratified in Australia since 2008 and there being a plain language version that can be used to communicate these rights to parents, as well as other legal and support services that could be accessed at this time.

## 5.0 Summary *continued*

A lot is known about what supports work best for parents with intellectual disability, yet the absence of services to provide best practice support is problematic.

*Cradle to Kinder* was cited as a useful support for many parents present at the meeting. Yet it is only available to parents 25 years or younger.

Participants in the meeting noted the importance of support being sustained over a long time, and provided at critical times (e.g., while pregnant in preparing for parenting, and when the child starts school). However, the gaps between what is offered and what should be available is wide.

As one participant in this forum described it, parents with intellectual disability going through proceedings where their parenting capabilities are being questioned by authorities can be a ***‘dynamic mix of heartache and misunderstanding’***.





**Parenting Research Centre**  
*raising children well*

# Positive Powerful Parents

## Report from the Hand In Hand Parent Meeting

Melbourne, 19 September 2018

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