Submission to the Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia

Advocacy for Inclusion

February 2013

About Advocacy for Inclusion

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion provides individual, self and systemic advocacy services for people with disabilities. We provide information, education, and representation to effectively advocate for positive and inclusive outcomes for people with disabilities.

We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned.

Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities*, and the *ACT Human Rights Act*.

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1. Develop rights based sexual health and family planning services that provide gender specific programs, which are accessible and targeted at people with disabilities.

2. Implement sex education for all children with disabilities in all schools from the early years of primary school and continued through high school.

3. Implement awareness training for health professionals on the reproductive, sexual and family rights of people with disabilities.

4. Improve awareness raising and training for service providers and support workers in the disability sector on the sexual and reproductive rights and privacy rights of people with disabilities.

5. Improve training and resources for parents, carers and guardians on how to support the sexual and reproductive rights of people with disabilities.

6. Develop combined sexuality and self-advocacy training programs for people with disabilities targeted at promoting their understanding and assertion of their sexual and reproductive rights.

7. Introduce explicit requirements under disability service legislation the *National Standards for Disability Services* that require service providers to support the reproductive and sexual rights of people with disabilities.

8. Introduce awareness raising and training for child protection workers, health professionals, legal aid family lawyers, and other legal and court staff on the rights of people with disabilities to found a family and raise their children with appropriate support.

9. Introduce comprehensive strengths-based and family-centred support for parents with disabilities, which are aimed at retaining children in the care of their parents, including supports that are long-term, prevention-focused and home-based.

Introduction

In Australia, and internationally, people with disabilities have a disturbing history of institutionalisation, segregation and oppression. This practice is tied to eugenic ideologies and practices, where people with disabilities were considered genetically inferior to the rest of society. People with disabilities were segregated from the community in institutions[1] and routinely sterilised to prevent them from reproducing "genetically inferior offspring".[2] Also used was the routine practice of forcibly removing children from parents with disabilities.[3]

Advocacy for Inclusion works with a number of people with disabilities who remain excluded or restricted in their sexual and reproductive rights. They are discriminated against on the basis of their disability by government and non-government service providers, carers, family members, and general members of the community. Advocacy for Inclusion provides advocacy support to people with disabilities to stand against this discrimination and to assert their human rights.

This submission is based on the experience of Advocacy for Inclusion in advocating for people with disabilities and in training them in self-advocacy skills to better assert their own rights.

The United Nations Convention on the Rights of Persons with Disabilities Article 23 states:

> *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.*

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[1] Richardson, M. (2005). Critiques of segregation and eugenics. In P. Goward, P. Gordon Ramcharan, *Learning disability: A life cycle approach to valuing people*. UK: McGraw-Hill Professional Publishing

[2] Llewellyn, G. & McConnell, D. (2005). You have to prove yourself all the time. In P. Goward, P. Gordon Ramcharan, *Learning disability: A life cycle approach to valuing people*. UK: McGraw-Hill Professional Publishing

[3] McConnel, D. & Bjorg Sigurjonsdottir, H. (2010). Caught in the child protection net. In G. Llewellyn, R. Traustadottir, D. McConnell, & H. Bjorg Sigurjonsdottir. *Parents with intellectual disabilities: Past present and futures.* UK: John Wiley and Sons.

> *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.*[4]

Like everyone else in the community, people with disabilities have the human right to retain their fertility, reproduce, raise their children, and receive support to do so.[5] Sexual expression is also gaining recognition as a fundamental human right. Paul Hunt, the former United Nations Special Rapporteur on the Right to Health, stated that he has:

> *no doubt that the correct understanding of fundamental human rights principles, as well as existing human rights norms, leads ineluctably to the recognition of sexual rights as human rights. Sexual rights include the right of all persons to express their sexual orientation, with due regard for the well-being and rights of others, without fear of persecution, denial of liberty or social interference.*[6]

People with disabilities have increasing access to their human rights, yet this history of oppression has created deep seated social perceptions and attitudes towards people with disabilities. People with disabilities are not understood as having the same sexual and reproductive rights as people without disabilities. Often they are actively discouraged from having sexual relationships and from founding a family. In sharp contrast, people in the general Australian population are expected to perform these roles as part of the natural course of life.

A societal misconception is that people with disabilities are child-like or asexual.[7] Conversely, when a person with disability is viewed as sexual they can be labelled as hyper-sexed or over-sexed. It is seen as a social problem to be supressed or eliminated.

The impacts of this history and the long-lasting community attitudes manifest as continued denial of sexual and reproductive rights for people with disabilities including:

- The removal of children from families based on the parent’s disability;
- Sterilisation;
- Forced and coerced abortions;
- Denial of access to sex education and family planning;
- Prevention from sexual expression; and,
- Prevented from establishing intimate relationships.

These practices are not “rare” or “a thing of the past” as many would like to think; they continue to happen in segregated environments hidden from the broader community.

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[4] United Nations. (2006). *Convention on the Rights of Persons with Disabilities.* Article 23.

[5] United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Article 23.

[6] Hunt, P. (2004). *Report of the Special Rapporteur on the Right to Health*. United Nations Office of the High Commissioner for Human Rights. UN Doc. E/CN.4/2004/49. www.unhchr.ch/Huridocda/Huridoca.nsf/(Symbol)/
E.CN.4.2004.49.En.

[7] Llewellyn, G. & McConnell, D. (2005). You have to prove yourself all the time. In P. Goward, P. Gordon Ramcharan, *Learning disability: A life cycle approach to valuing people*. UK: McGraw-Hill Professional Publishing

Lack of sex education and family planning services

A major barrier for people with disabilities in accessing their sexual and reproductive rights is a lack of access to appropriate sex education and family planning services. The assumption that people with disabilities do not, or will not, need these services has left many without access to these programs.[8] All jurisdictions in Australia have a sexual health and family planning organisation. However, many of these organisations lack the funding to provide services that are comprehensive, appropriate and targeted at people with disabilities, particularly those which are rights based and gender specific.[9]

People with disabilities also have needs for these services, especially women considering their particular reproductive needs. Some require information and education in formats that meet their specific learning needs. Many also need these services over the course of their life-time rather than on one occasion, beginning from the early years of primary school and throughout adulthood. Such services are extremely limited across Australia and existing programs are not provided in all primary and high schools. Standing programs tend to be targeted at service providers, parents and carers; this is highly worthwhile but does not in any way replace the need for programs for people with disabilities.[10]

Women with Disabilities Australia explains that current practices are generally characterised by:

> *limited voluntary contraceptive choices, a focus on menstrual suppression, poorly managed pregnancy and birth, involuntary abortion, forced sterilisation, and the denial of rights to parenting. These practices are framed within traditional social attitudes that characterise disability as a personal tragedy or a matter for medical management and rehabilitation*[11]

As a result, some people with disabilities do not understand their reproductive health needs, their rights and boundaries in relationships and in the community, and the basics of safe and healthy relationships. For example, some consumers at Advocacy for Inclusion have never been informed that they should get pap-smears until later in their adult life. Alarmingly, many consumers have been sexually assaulted or raped and were unaware that this was wrong because they had never been afforded sex education at school.

Recommendations

1. Develop rights based sexual health and family planning services that provide gender specific programs, which are accessible and targeted at people with disabilities.

2. Implement sex education for all children with disabilities in all schools from the early years of primary school and continued through high school.

3. Implement awareness training for health professionals on the reproductive, sexual and family rights of people with disabilities.

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[8] CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

[9] Women with Disabilities Australia. (2011). *Submission to the UN analytical study on violence against women with disabilities*. www.wwda.org.au/WWDASubUNStudyViolenceWWDDec2011.pdf

[10] Women with Disabilities Australia. (2011). *Submission to the UN analytical study on violence against women with disabilities*. www.wwda.org.au/WWDASubUNStudyViolenceWWDDec2011.pdf

[11] Women with Disabilities Australia. (2009). *Parenting Issues for women with disabilities in Australia - A policy paper.* www.wwda.org.au/motherhd2006.htm

Oppression of sexuality

Consumers at Advocacy for Inclusion are denied the right to sexual expression and sexual relationships purely on the basis of their disability. This stems from the broader societal misconception that people with disabilities are not or should not be sexual. People with disabilities are also perceived as vulnerable and childlike, which leads to a paternalistic preoccupation with overprotecting them.[12] This is particularly a problem for individuals who live in supported accommodation arrangements such as group homes. Their lives are heavily influenced by organisational practices and rules that can ignore, control or directly block their sexual and reproductive rights.

The *CRPD Civil Society Report* notes the systemic issues in Australia that interfere with the sexual and reproductive rights of people with disabilities in supported accommodation facilities:

- *Prejudice among support staff, who believe or assume that people with disabilities do not engage in sexual relations or activities;*
- *Preoccupation with risk management and not enough attention paid to supporting the rights of people with disabilities;*
- *Organisational policies and practices that prevent the sexual expression of people with disabilities in their own homes;*
- *Lack of respect for the right to privacy of people with disabilities in supported accommodation facilities. This includes when support workers access a person's bedroom and personal belongings without permission.*[13]

These experiences are shared by Advocacy for Inclusion consumers. Family members and unpaid carers of people with disabilities also prevent access to sexual and reproductive rights, particularly for people under guardianship orders, where a person with a disability is legally deemed to lack 'capacity' and therefore their decision making rights and responsibilities are removed and assigned to a guardian.

The case studies below reflect real cases at Advocacy for Inclusion but have been de-identified for privacy purposes.

Krisha

Krisha lives in supported accommodation run by a non-government disability service. She has lived there for 10 years. She recently met a partner whom she wants to bring home to stay the night. The service provider has explicitly told her that she CANNOT have her partner stay over or have sexual relations at home, even though she intends to do this in the privacy of her bedroom, as she lives with a house mate.

Krisha's advocate complained to the service provider, explaining that it is Krisha's right to have these relationships in her own home. The service provider had a number of excuses for the "no sex rule" including that this is what Krisha agreed to when she moved into the home 10 years ago and that it will impact on the safety of her house mate. The provider says that Krisha should do it somewhere else. "Do you really want to do this, Krisha? Remember what you agreed to when you moved in? It's really not fair for you to change your mind now" the provider says.

Krisha is unsure if she really has the right to sexual expression no matter how much her advocate tries to reassure her. She decided to give up because she worries about the consequences if she takes it further. "They might kick me out if I keep going on about it. They make me feel like a child" she explains "but I suppose I have to put up with it."

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[12] Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability: Untold desires*. London, New York: Cassell.
[13] CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

Saul and Tanya

Saul and Tanya lived in separate supported accommodation group homes run by the same disability service provider. They began dating a few months ago and decided that they want to have a sexual relationship and stay over at each other's home a few nights a week. The support staff were concerned at first. They wondered about the risks of pregnancy and other sexual health needs and how this related to their duty of care. It was not easy for Tanya and Paul to see each other at this time because staff were unsure whether to support it. Saul and Tanya negotiated with the service provider and support workers before they became comfortable with the idea. They all came up with a plan for Tanya and Saul to stay at each other's house that works with the household routines and staff rosters. Eventually the service provider and staff were happy to support the couple to have their relationship. Tanya and Saul were pleased with the arrangement although it was heavily regimented.

Both of these case studies demonstrate the level of control supported accommodation providers can have over the sexual and reproductive rights of people with disabilities. When support workers and service providers hold the common societal perception that people with disabilities are asexual or need to be protected from sex, this prevents the development of intimate relationships and the expression of sexuality.

Disability supported accommodation is seen as a workplace environment by many service providers; so even when support workers are supportive of the sexuality of consumers, the organisational structures and culture of the "workplaces" they work within cause barriers for people with disabilities to express their sexuality and relationships. These barriers do not exist for the broader community who live in "homes" rather than "workplaces".

The level of dependence consumers have on accommodation support providers means people with disabilities are not in a position where they can readily complain to have such issues addressed. Some people with disabilities become oppressed through these practices and develop the belief that they do not have the right to express their sexuality.

Raj

Raj has trouble understanding the social rules for when and where it is appropriate to engage in sexual expression because of his disability. It has caused him to be expelled from his TAFE course and is impacting his life significantly. He has never accessed any counselling about this and the issue has gone undealt with until now. His father has decided to apply for a guardianship order so that Raj can be medicated to supress his libido. "It has gone too far. It is in his best interests. He might wind up in jail one day!" his father says. Raj's advocate suggests trying sexual health and relationship education and counselling instead of medication. "He is like a child; education and counselling is not going to help" his father justifies.

The sexuality of people with disabilities is regarded as a problem that must be controlled and managed. When a person with disability has difficulty in understanding social expectations and boundaries with sexual expression, often the most invasive measures such as medication and sterilisation are explored by parents, carers, and guardians rather than supportive measures such as education, counselling, and other social supports.

Lee

Lee recently turned 19. Her mum has always bought her clothes for her and she doesn't like them. She wants to dress in trendy clothes like other young women her age do. Her support worker went shopping with her and helped her to buy some new clothes and underwear. Lee bought herself some lingerie, a mini dress and a pair of skinny jeans. She was really excited about it and was pleased with her new items. "I can wear the dress out for dinner one night!" But when her mother found her new clothes in her wardrobe she was upset with Lee and her support worker. "Lee, you can't wear this. It is totally inappropriate" her mum said. She made Lee and the support worker return the clothing and lingerie. Lee was very upset and embarrassed that her mum had seen what she bought.

Armando

Armando lives in disability supported accommodation. His mother has a great deal of control over his sexuality, which she exercises through the supported accommodation provider. He has begun locking away his pornographic magazines and DVDs because support workers go into his room, find them, remove them, and "get angry" at him. "Mum has told them that I'm not allowed to have it at home. I feel really guilty but other adults are allowed to have porn, aren't they?" One time he asked a support worker to transport him to an adult store. The support worker did so but the service manager transferred the worker to another home when his mother found out. His mother told him that he is not to ask support workers to do that again.

Parents and carers sometimes have a hard time seeing the person with disability as a sexual being and will oppress their sexuality, fearing that it is problematic or inappropriate. This includes breaching their privacy in ways that other adults would never accept and interfering with the person's private activities. Service providers often answer to parents, carers and guardians and will act on their instructions instead of the person with disability. This also includes people with disabilities who do not have a guardian.

Tamara

Tamara has a cognitive disability and was living with her boyfriend, who became violent towards her. Like many other women in this situation she found it difficult to leave him. She loves him and wanted to try to make it work. Tamara's sister was very concerned about her wellbeing, but instead of assisting her to access information, supports and options for pathways to safety, her sister made an application to ACT Civil and Administrative Tribunal for a guardianship order. The ACAT made a guardianship order and her sister was assigned decision making responsibility for Tamara's accommodation. The guardian was legally able to make decisions about where and with whom Tamara lives. Her sister placed her into a supported accommodation group home against Tamara's will so that she would no longer live with her boyfriend. Tamara is devastated and feels like she has no rights at all to choose an intimate partner like people without disabilities do.

People with disabilities are prevented from experiencing the same sexual and relationship activities and risks as people without disabilities. This is because people with disabilities are seen as child-like and vulnerable, and others have a tendency to overprotect them. As shown in Tamara's case study, guardianship practices can directly prevent a person with disability from having a relationship. Although her relationship was an unsafe one, women without disabilities should be able to make their own decision about whether to stay in or leave these relationships like any woman, unlike Tamara who had that right taken away from her.

Recommendations

4. Improve awareness raising and training for service providers and support workers in the disability sector on the sexual and reproductive rights and privacy rights of people with disabilities.

5. Improve training and resources for parents, carers and guardians on how to support the sexual and reproductive rights of people with disabilities.

6. Develop combined sexuality and self-advocacy training programs for people with disabilities targeted at promoting their understanding and assertion of their sexual and reproductive rights.

7. Introduce explicit requirements under disability service legislation the *National Standards for Disability Services* that require service providers to support the reproductive and sexual rights of people with disabilities.

Denial of reproductive and parenting rights

Many Advocacy for Inclusion consumers are parents with disabilities, who have had their children removed and placed into foster care on the basis of the parent's disability. Other consumers are constantly at risk of having their children removed by child protection services and have only allayed removal because of the persistence of an advocate challenging the attitudes and assumptions about people with disabilities. Child protection agencies believe that a person cannot or should not parent because of their disability. This is related to the common societal attitudes towards people with disabilities regarding them as asexual and child-like. This makes it difficult for community members to imagine that people with disabilities have parenting rights and responsibilities.[14]

A growing body of evidence shows widespread discrimination and severe lack or total absence of appropriate supports for parents with disabilities. A study by Llewellyn, McConnell and Ferronato[15] at two Children's Courts in NSW revealed that parents with cognitive disabilities were involved in almost one third of child protection cases. The study found a disproportionate amount of children of parents with intellectual disabilities were placed on wardship orders and outside of the family network.

The researchers concluded that the overrepresentation of parents with disabilities in child protection proceedings relate to apparent discriminatory attitudes towards parents with disabilities in the court system and among child protection agencies, including the belief that parents with intellectual disabilities cannot learn parenting skills.[16] This belief is based on prejudice against people with disabilities as it is not empirically evidenced and there is a significant amount of refuting empirical research.[17] [18] [19] Parents with disabilities are unjustly having their children removed based on the ill-informed judgement that they cannot learn new skills.

Advocacy for Inclusion finds that child protection services take action and make recommendations based only on perceived risks rather than actual instances of abuse or neglect. Likewise, in 2012, Colleen Pearce, Public Advocate of Victoria, states:

> *I am increasingly concerned that children are being removed from parents with a disability based solely on that disability, and not because the cases meet the relevant tests… Very often their child is removed not because the parent has harmed or neglected them, but because the child is seen as being at risk of neglect. The appropriate response to this is to provide support, encouragement, help and education*.[20]

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[14] Llewellyn, G. & McConnell, D. (2005). You have to prove yourself all the time. In P. Goward, P. Gordon Ramcharan, *Learning disability: A life cycle approach to valuing people*. UK: McGraw-Hill Professional Publishing

[15] Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, *27*(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

[16] Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, *27*(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

[17] Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectually disability: A randomised controlled trial. *Research in Developmental Disabilities, 24*(6), 405-431.doi: 10.1016/j.ridd.2003.06.001

[18] Monsen, K., Sanders, A., Yu, F., Radosevich, D., & Geppert, J. (2011). Family home visiting outcomes for mothers with and without intellectual disabilities. *Journal of Intellectual Disability Research, 55*(5), 484-499. doi: 10.1111/j.1365-2788.2011.01402.x

[19] Tarleton, B., & Ward, L. (2007). "Parenting with support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 194-202. doi: 10.1111/j.1741-1130.2007.00118.x

[20] Pearce, C. (15 December 2012). Disability no bar to good parenting. *The Age.* www.theage.com.au/opinion/politics/disability-no-bar-to-good-parenting-20121214-2bf75.html

The information existing in Australia and internationally overwhelmingly indicates that many parents with disabilities lack support to parent.[21] [22] [23] In the Australian court study, the lack of support services available often directly resulted in child removal because the parents were not considered competent without supports.[24] Numerous studies, including one in Australia, indicate that existing services accessed by parents with disabilities, such as child protection agencies, are incomprehensible to people with disabilities, judgemental, intimidating and disrespectful. Many people report feeling doubted and not listened to.[25] [26] [27] [28]

This lack of appropriate and supportive services is a major barrier for parents at Advocacy for Inclusion. Child Protection Services are considered adversarial because they are often preoccupied with the parent's disability and parenting deficits, and do not apply enough attention to parent and family strengths. They often focus narrowly on the child's rights as totally separate from the parents to the detriment of due consideration for the parent's rights. Many parents with disabilities require services that are:

- Home based
- Prevention focused
- Strengths based
- Long-term
- Family centred
- Flexible.[29]

Services with these qualities are widely unavailable which directly results in the removal of children from parents with disabilities.

Advocacy for Inclusion attended the Disability Advocacy Network Australia (DANA) conference in April 2012. A woman with disability shared her story about the denial of her parenting rights by health professionals and statutory authorities. She was coerced into the abortion of her first child by prenatal health professionals, who convinced her that she should not have the baby. She was denied the information she needed about her options to make an informed decision. She placed her trust in them as the 'expert' and did as they advised. Her second baby was immediately removed at birth by child protection services without even giving her the opportunity to develop her parenting skills, let alone providing her with the information and support she needed to raise her baby. Her child was eventually returned after she "proved" that she could care for her child with support. The impacts on her and her child's life have been devastating.

The right to parent is an issue inextricably linked with the practices of forced and coerced sterilisation because it correlates directly to the prevailing attitude that people with disabilities will not or should not be parents. Advocacy for Inclusion is aware that one submission into this inquiry illustrates these attitudes and issues:

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[21] Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system: Experiences and perspectives. *Journal of intellectual disabilities*, 9(2), 109-129

[22] Gore, N. (2010). Building effective support for learning disabled parents. *Community Care,* (1844), 34-35.

[23] Starke, M. (2010). Encounters with professionals: views and experiences of mothers with intellectual disability. *Journal of Intellectual Disabilities, 14*(1), 9-19. doi: 10.1177/1744629510373052

[24] Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, *27*(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

[25] Booth, T., & Booth, W. (2004). Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1*(3–4), 179–181. doi: 10.1111/j.1741-1130.2004.04032.x

[26] Starke, M. (2010). Encounters with professionals: views and experiences of mothers with intellectual disability. *Journal of Intellectual Disabilities, 14*(1), 9-19. doi: 10.1177/1744629510373052

[27] Tarleton, B., & Ward, L. (2007). "Parenting with support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 194-202. doi: 10.1111/j.1741-1130.2007.00118.x

[28] Wade, C. M., Mildon, R. L., & Matthews. (2007). Service delivery to parents with an intellectual disability: Family-centred or professionally centred? *Journal of Applied Research in Intellectual Disabilities, 20*(2), 87-98. doi: 10.1111/j.1468-3148.2005.00297.x

[29] Lamont, A., & Bromfield, L. (2009). *Parental intellectual disability and child protection: Key issues*. National Child Protection Clearing House, (31), 1-18. www.aifs.gov.au/nch/pubs/issues/issues31/issues31.html

> *The inquiry has so far received just five submissions, including one from a parent explaining her wish to have her 27-year-old intellectually disabled daughter sterilised.*
>
> *"Her own life is not stable enough to support another life," the parent wrote. "Advocates who say she has the 'right' to have a child need to factor in her ability to be responsible for that child."*
>
> *The author said they had already raised three children, but at 54 did not want to raise their grandchild. "Sterilisation of my daughter is one thing that I can ensure for her before I die, otherwise who will?"*[30]

Below are case studies that reflect real cases at Advocacy for Inclusion, which have been de-identified to protect privacy.

Dreena

Dreena's first child was removed by child protection services when the child was a couple of months old. Child Protection first became involved when she had a routine appointment at the hospital during her pregnancy; the midwife made a report to Child Protection concerned about the child's welfare because she has an intellectual disability, despite no evidence to suggest that she would not be a loving and caring parent. The midwife always reports pregnant women with intellectual disabilities to Child Protection.

Child Protection met with Dreena while she was pregnant and asked her about who else might be able to take care of the baby for her, such as a family member. They suggested that a kinship order may be a good idea to give parental responsibility to a trusted family member. Dreena was shocked and explained that she intends to keep and raise the baby herself. Child Protection told her that it might be something worth exploring in the future if she has difficulties caring for her baby.

After a few months Child Protection services became concerned when her baby was not putting on enough weight. Dreena was concerned about this too as she had difficulty breast feeding and knowing how much formula he needed. The most support Dreena received in relation to this was a few parenting classes. Because of her learning difficulties, this "classroom" style education did not really help. "I needed support at home" she explains "someone who can show me how to do it."

Child Protection Services required her to go to a hospital based program for a couple of nights. This is where her parenting capacity was observed and assessed. At no time was she actively assisted. She felt intimidated. Child Protection reports note that her struggles include leaving her baby in a soiled nappy for a prolonged period and having difficulty understanding her baby's nutritional needs. On the last morning at the program she recalls the traumatic experience when Child Protection arrived and took her son away immediately. She remembers screaming and crying as they took him away. She couldn't breathe and she was in total shock. "I thought they were there to help me. I didn't know they were going to do that."

A court process ensued and the child protection authority applied for final orders to remove her son until he turned 18:

"Care and Protection records demonstrate that Ms Angelis loves her son dearly, has tried hard to be a good mother and to maintain him at home. Evidence also highlights limitations in her parenting capacity however, which result from her low intellectual capacity and translates to her being unable to provide for her son's needs." *(CPS report to Court).*

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[30] Chadwick, V. (2 January 2013). Rush to sterilise mentally disabled horrifies doctor. *Sydney Morning Herald*. www.smh.com.au/national/rush-to-sterilise-mentally-disabled-horrifies-doctor-20130101-2c45o.html

Dreena's son is still in foster care. She sees him every month without supervision and they always have a good time together. It is always hard for her to see him leave. He often says that he wants to come home to her but she will have to take it to court again to have the orders overturned. Here she will come up against the same prejudice she faced when her child was removed – the assumption that her intellectual disability makes it impossible for her to parent. Legal Aid denied her first application to take it to court and named her intellectual disability as one of the reasons her case would not succeed.

Dreena's case demonstrates the prejudice she experienced at various stages of her parenthood:

- During her pregnancy the health professional decided that Child Protection Services should be involved due to her intellectual disability;
- Before Dreena gave birth, Child Protection assumed that she may not be able to care for her baby because of her disability and that a family member may make a more appropriate parent;
- Child Protection judged some of her parenting difficulties more harshly than they would for a parent without disability. They assumed that these difficulties could not be improved because of her disability without first providing her appropriate support;
- The court made the judgement that her child should be removed and would be better cared for in a foster placement;
- She continues to face barriers in appealing that decision due to assumptions about her intellectual disability and parenting capacity.

The stories of other parents across Australia and the existing research shows that Dreena's experience is not unique and is closely related to widespread discrimination.

Salina

Salina and her partner of seven years have decided that they want to have a baby soon. Salina's family was alarmed by this and told her that she really should not be having a baby. "That really hurt me. Most people get excited about having a baby but my family told me it was a bad idea because of my intellectual disability."

Salina's mother wants to go with her to the doctor to talk about contraception options. Salina doesn't want to go to the doctor because she is happy with the contraception she is already on. "Mum is constantly hassling me about it. She was looking through my bathroom cabinet to see what I'm taking but it's none of her business. This is private stuff." Her mother is pressuring her to get a "procedure" done to stop her from getting pregnant.

Her mother called Salina's case manager, whom Salina has a good relationship with, and asked her to talk to Salina about it. Her case manager told her that it is a bad idea for her to get pregnant "think about who is going to look after it. Are you? It's going to be too hard for you."

Salina refuses to get the procedure done but she is now reconsidering her plans to have a baby. "Everyone thinks it's a bad idea. Mum says child protection services will have to take my baby away if I get pregnant. So I suppose I don't really have a choice."

At Advocacy for Inclusion parents experience a strong resistance towards their parenting rights by family members and service providers. Sometimes family members in conjunction with service providers and health professionals will provide people with disabilities inaccurate or incomplete information in order to coerce them to stop having children or even to get them to sign over their parenting responsibility to the state or another family member. It prevents them from accessing family planning support in the same ways as people without disabilities do.

People with disabilities are coerced into undertaking procedures or treatments to prevent pregnancy because they are led to believe it is the best or only option. Often family members and service providers do not consciously realise that they are doing this as they genuinely believe that the person should not have a baby. These beliefs come from the deeply seated prejudice that people with disabilities do not have parenting rights and responsibilities, which lead members of the community to deny these rights and responsibilities.

Recommendations

8. Introduce awareness raising and training for child protection workers, health professionals, legal aid family lawyers, and other legal and court staff on the rights of people with disabilities to found a family and raise their children with appropriate support.

9. Introduce comprehensive strengths-based and family-centred support for parents with disabilities, which are aimed at retaining children in the care of their parents, including supports that are long-term, prevention-focused and home-based.

Conclusion

The history of eugenic ideologies and practices has the long-lasting effect of continuing oppression of sexual and reproductive rights of people with disabilities by the community and by those who support them directly.

There is a continuing belief among some of the people closest to people with disabilities, such as their families and carers, that sterilisation and related practices including medications to supress libido are viable first options.

At the same time, people with disabilities do not have access to adequate services that offer supportive and human rights compliant alternatives. This includes sex education and counselling, and family planning services. Many people with disabilities are denied their right to privacy, to form intimate relationships, to engage in sexual expression, and to found a family.

Service providers and family members directly interfere with a person’s rights, but this is hidden behind the closed doors of their family home or in supported accommodation facilities. Statutory authorities have the power to forcibly remove children from their families and do so based on the parent’s disability.

This issue remains widely unknown to the general public. Forced and coerced sterilisations and abortions are among the most horrific forms of sexual and reproductive oppression but are only one part of a much broader problem for people with disabilities.

Without broad based and widely available sexual and reproductive health education and supports, people with disabilities will continue to have their rights denied, including the right to be active sexual beings, to have intimate relationships, form families and be in control of their own fertility.