

PROJECT OVERVIEW

Children by Choice X WWILD Collaboration

Pregnancy decision-making support for pregnant people with intellectual and learning disability experiencing reproductive coercion and abuse.

November 2021

This project is being driven by an ongoing collaboration between Children by Choice and [WWILD Sexual Violence Prevention Association](#), who provide Disability Royal Commission, Victims of Crime and sexual violence prevention support programs for people with intellectual disabilities.

The (WorkUP funded) project began with a curiosity: why were people with intellectual disability under-reported in Children by Choice counselling client data, despite being more likely to experience reproductive coercion and abuse (RCA) and sexual violence? We sought to understand how to improve pregnancy decision making support for this group, and meet sector and consumer needs, through collaboration and knowledge sharing. We conducted focus groups with people with intellectual disability and Queensland-based domestic and family violence and sexual assault support service workers. The project to date has involved:

- Review of existing resources on pregnancy decision making for people with intellectual disability
- Systematic literature review: Reproductive autonomy and pregnancy decision making for pregnant people with ID living with violence or RCA
- Focus groups and interviews - WWILD & other disability-based service users
- Focus group consultation with Queensland Domestic and Family Violence & Sexual Assault and Children by Choice counselling services to identify practice needs/gaps
- Presented findings at [WorkUP Spark Webinar](#) for Sexual Violence Awareness Month, [Australasian Society for Intellectual Disability STOP DV conference](#)

INITIAL FOCUS GROUP FINDINGS

Common Individual Experiences

The majority of participants had become pregnant as a result of sexual violence, either by strangers or partners.

Focus Group participants also reported:

- Limited knowledge about, and informed decision-making regarding reproductive health and choices.
- RCA, demonstrated in reports of restricted access to and physical removal of contraceptives by partners (resulting in pregnancies), forced contraception, and refusal to use or non-consensual removal of condoms.
- Pressure to terminate pregnancies by family members and professionals.
- Late identification of pregnancies (two participants).
- Feelings of shame.
- Not feeling supported or in control:

“Just the way that they approached me I suppose. ‘Are you sure that you really want your tubes tied’ at the same time I was having my C section? They keep saying—‘Oh no are you gonna have another baby?’. And I was like ‘100% you’re doing the whole thing there at once’. Questioning my judgement that a 38 year old would know what she was doing. You know I know exactly what I was doing. They kept pushing me.”

- Child removal as the most common response to continuing a pregnancy, along with shared care arrangements:

“When I was pregnant, everyone was against it. They wanted me to abort it, or put it in foster care. Because they didn’t give me a reason. And um, I got lied to about how they were going to take it away.”

Existing Systems Knowledge

- Focus group participants demonstrated some domestic and family violence and sexual assault (DFVSA) literacy, with most having received support from WWILD or other disability services.
- No participants had used mainstream DFVSA services, nor did they wish to. More likely to seek help for DFVSA from disability and medical services.
- Participants sought help for RCA from friends, family, support workers, social workers, general practitioners (GPs) and/or the police.
- Participants had little or no knowledge of
 - reproductive coercion and/or reproductive rights.
 - pregnancy options – some referenced abortion, adoption, and kinship/care, although not by formal names.
 - the realities and practicalities associated with parenting.
 - contraception options.

Areas of unmet need

"when you are single and you got a disability and you are pregnant, like—what do you do?"

Participants identified wanting and needing:

- Resources to read or watch to learn about pregnancy.
- Easy English resources.
 - "When you can't understand something properly, they should explain it better."*
 - "You got the doctors around you. They go all over your head and this and that. What's going on? All this jargon stuff...you get mixed up about what you can and can't do."*
- More information on pregnancy, including videos of people with disabilities talking about pregnancy options, including having a baby and parenting.
 - "Pictures.... if you have a disability, it's probably a lot more... seeing the video, of a baby getting born would probably be very scary for people who don't have that support or anything."*
- Pregnancy and parenting classes and support for people with intellectual disability.
- Supported, informed decision-making:
 - "Abortion. I've done that. I had that decision on my own with my social worker. She printed everything off for me ... and she made the call with me."*
 - "When you go to the doctor, if you've got a support worker, they look at the support worker and not you. It's like, I'm here. I'm the patient. Excuse me, it's about me!"*
- True informed choice is when you know the realities of what parenting will be like.

Systemic Issues

<i>DFVSA Staff & consumers know:</i>	<i>Consumers would add:</i>
<ul style="list-style-type: none"> • Safety planning & care arrangements when a carer is the person using violence or intervention order present needed • Lag time for NDIS funds for alternative care or services • Tension between consumer & family wishes • Consumer may not disclose intellectual disability • Thoughtful ways to adapt practice needed 	<ul style="list-style-type: none"> • Will child safety be notified? • Be transparent about roles & responsibilities (mandatory reporting) • Need more education about pregnancy, childbirth & parenting • Mainstream services lack knowledge & practice skills • Health care professionals assume incompetence and don't trust women to know what they want • Not enough accessible resources for people in violence relationships/experiencing RCA