

2021 - 2022

DASHER PROJECT

Easy English Sexual & Reproductive Health
Resources for People with Disability



Interactive resources
co-designed with
women with
disabilities

CHILDREN BY CHOICE
ASSOCIATION INCORPORATED

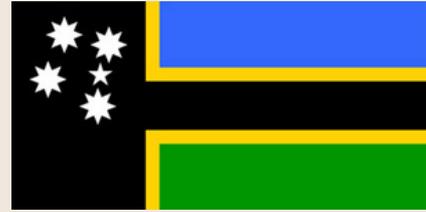


Acknowledgement of country

Children by Choice acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of Country throughout Australia and the continuing connection to lands, waters and communities.

In particular, we acknowledge the country north and south of the Brisbane River, as the home of both the Turrbul and Jagera nations. We pay our respect to them, their culture, and to their Elders both past and present.

ALWAYS WAS, ALWAYS WILL BE ABORIGINAL LAND



Acknowledgement of co-creators and collaborators

Children by Choice acknowledge the women who participated and collaborated with us on this project. They provided invaluable insights into their cultural sensitivities and the gaps in knowledge regarding sexual and reproductive health available to their community. They were vital to the co-creation process of the resources. Without the participants, this project could not have been completed.

Table of Contents

Introduction.....	4
Project Evaluation.....	5
Key Program Benefits.....	7
Feedback.....	11
Next steps.....	11
Learnings & recommendations..	12
Links to Resources.....	17
References.....	18

Introduction

The DASHER project, funded by 100 Women, is a practice and research integrated project that began in early 2022 in partnership with WWILD SVP.

People with disabilities face significantly higher rates of violence and lower levels of reproductive health literacy, putting them at risk of unintended pregnancy, late pregnancy identification, sexual violence and coerced pregnancy outcomes. Focus groups with women with intellectual and learning disabilities identified an unmet need for accessible, Easy English resources providing information on pregnancy options, contraception, consent and reproductive coercion and abuse to support informed decision making, reproductive autonomy and the realisation of their reproductive rights. The project involved running a series of focus groups to develop and test 4 printable Easy English resources that can be used by health and social care providers to support reproductive literacy and informed decision making among this community. We also worked with Griffith University to collect and interpret the stories of women with intellectual disabilities about accessing sexual and reproductive health care and making pregnancy decisions, to begin to fill a significant gap in research on this topic, in Australia and globally.

Start date: January 4, 2022

End date: October 31, 2022 (with dissemination and research ongoing)

Project Evaluation

Planned Outcomes

The project met its planned outcomes and resulted in a successful additional grant provided by the Queensland government Office for Women to extend the project. As such, aspects of the dissemination plan have been delayed while we expand the suite of resources.

Children by Choice facilitated a total of 4 focus groups and 4 interviews with 15 women with intellectual and learning disabilities and difficulties across the project duration, exceeding our goal of including 6 women in the co-design process. This led to the co-design of four easy English resources spanning topics of pregnancy options, contraception, reproductive coercion and abuse and consent.

The partnership between Children by Choice and WWILD Sexual Violence Prevention ensured all work was collaborative and in line with best practice principles of inclusive design and met the needs of the intended population. The partnership facilitated a trauma-informed approach to recruitment the running of focus groups as we were able to have counsellors, researchers and disability support workers in all sessions. This further enabled access to onsite counselling during or after all focus groups sessions for participants who required and requested it. The partnership gave project staff access to training in Easy English resource development and ensured lived experience was embedded into all processes. We collaboratively developed a style of resources that both met key Easy English guidelines as well as the preferences of women with intellectual and learning disabilities, who wanted more detail and information than traditional Easy English standards allowed. In doing so we ensured the resources met the reproductive autonomy and information decision making needs of women with intellectual and learning disabilities and difficulties.

While the initial grant described a plan to adapt existing Easy English resources, due to feedback from focus groups we developed 4 new resources from scratch that enabled the project to effectively meet the needs of the community and reflected up-to-date evidence-based practice. The budget planned to pay for copyright was redirected into the development of new resources.

While the initial project plan described a 'sector-wide' dissemination workshop, after consultation with our partner organisation and a desire to maximise the usability of the resources by a range of multi-sectoral professionals, we instead ran a series of activities with health, violence, and disability practitioners.

This included two focus groups with 14 health and domestic violence practitioners from a range of organisations across Queensland who fed into the resource development and gave advice and information on the practicalities of implementation. This led to the development of a two page “advice for use” PDF document that is being distributed with the resources and will be available online to support practitioners to use them to their greatest effect in practice. Professionals gave significant input into the content, best-practice and accuracy, and also fed into a plan for dissemination that considered the realities of appointment times and contact methods across a range of service types.

We were also invited to present the work and process to two professional industry groups (The Australian Association of Social Workers and the Australasian Society for Intellectual Disability) via 2 x 1.5-hour webinars, which resulted in ongoing partnerships and built demand for the resources, further expanding the sector’s knowledge of what is possible in research and co-design with genuine collaboration and appropriate funding.

We received ethical approval to use the data gathered through the focus groups for research purposes and are in the process of writing up the findings and developing a manuscript (research paper), which will be submitted to an academic journal later in 2022.

Due to staff changeover, COVID-19, and winning an additional grant to expand the work of this project, the timelines have been delayed. We are currently awaiting the final resources from the graphic designer employed to finalise the resources. Children by Choice is also now working on turning the resources into short videos with the support of the additional grant, which was explicitly requested by participants in the focus group sessions. Further feedback by professionals in the focus groups included a request to create ‘flip chart-appropriate formatting’ that could be used when they run training in the sector. Children by Choice further secured additional funding to create a small take-home printed booklet, and we are turning all the printable resources into hard-copy printed A5 booklets as well. Women with intellectual and learning disabilities and difficulties asked for these specifically so they could support their own children to understand the concepts, and professionals are excited to have these more client-appropriate take-home assets to distribute in their services.

Due to the project’s expansion and delays with contractors, some of the outcomes discussed below are conservative estimations as to the reach of the resources and distribution planned to occur during November and December 2022.

Inputs

- Project worker at 1 day a week (0.2FTE) for the duration of the project
- WWILD staff – project planning, focus group facilitation, interview recruitment, document review and editing, co-presenting at conferences and webinars
- \$180 gift cards for all focus group participants (women with intellectual and learning disabilities and difficulties) in line with consumer engagement standards in health
- Catering, travel, childcare and support worker costs for participants
- \$80 reimbursement (provided in kind by Children by Choice) to all professionals who participated in online focus groups
- Funding for graphic design
- Funding and hours for conference travel
- \$1000 in kind from Children by Choice as reimbursements for attendees of the professional focus groups
- Additional input and supervision from Children by Choice CEO and Education team.

Activities

- 4 x focus groups and 4 x individual interviews with women with intellectual disabilities who had experienced violence (15 women in total)
- 2 x focus groups with 14 health, domestic violence and disability professionals
- Drafting and re-drafting 3 times the 4 Easy English printable resources
- Development of 'instructions for use' document to accompany resources on distribution (in progress)
- Attendance at 4 hours of training on Easy English resource best practice
- Collection of 10 hours of interview data
- Qualitative data analysis of interview data
- Writing a manuscript for submission in an international academic peer-reviewed journal
- Delivery of 2 webinars to professional industry groups (20 attendees each)
- Presentation of the project at 2 conferences

Outputs

- 4 resources + instructions for use document
- Manuscript (in progress) for publication in a peer-reviewed journal
- 14 participants – members of the Australian Association of Social Workers, at a 1.5-hour webinar on the project process and findings
- 25 participants – members of the Australasian Society for Intellectual Disability, at a 1.5-hour webinar on ethical, inclusive research practices, and program outcomes, for their membership
- 14 health, violence, and disability professionals, attended 2 x online focus groups
- Approximately 40 of 250 delegates at the Reproductive Rights and Abortion Conference 2022.
- Approximately 30 delegates at the Australasian Sexual Health Conference 2022
- Active distribution (in progress) of resources to our networks throughout Queensland, Australia, and via WWILD and CbyC's websites and social media platforms.

Outcomes

- Increased knowledge and understanding of consent, reproductive coercion and abuse, contraceptive options and pregnancy options among 14 women with intellectual and learning disabilities and difficulties
- Increased knowledge and understanding of effective communication and education processes when working with clients with low levels of English literacy for 53 health, violence and disability sector professionals
- Empowerment of professionals to support the improved reproductive health literacy of clients with low levels of English literacy, including women with intellectual and learning disabilities and difficulties.

Key Program Benefits

While dissemination is in progress, and thus outcomes are challenging to measure, there are several key program benefits that have been shared with us:

- The most surprising and encouraging feedback has been from health, domestic violence, and disability sector professionals, who spoke in the groups about their increased confidence to support informed decision making, reproductive autonomy and health literacy among clients with disabilities because of having the resources to use in consultations and to distribute. They also reported feeling excited to use the resources in their own group trainings and have asked for the resources in a range of formats to be used not only with clients with disabilities but a wide range of client groups with low levels of English language literacy.
- Given these are the first resources of their kind in Australia, and the overwhelmingly positive feedback from providers, we anticipate the reach and impact of resources on practice, from doctors to violence services to schools, will be beyond what we could have hoped.

Women and organisations involved

15 women with intellectual and learning disabilities and difficulties engaged in the co-design process

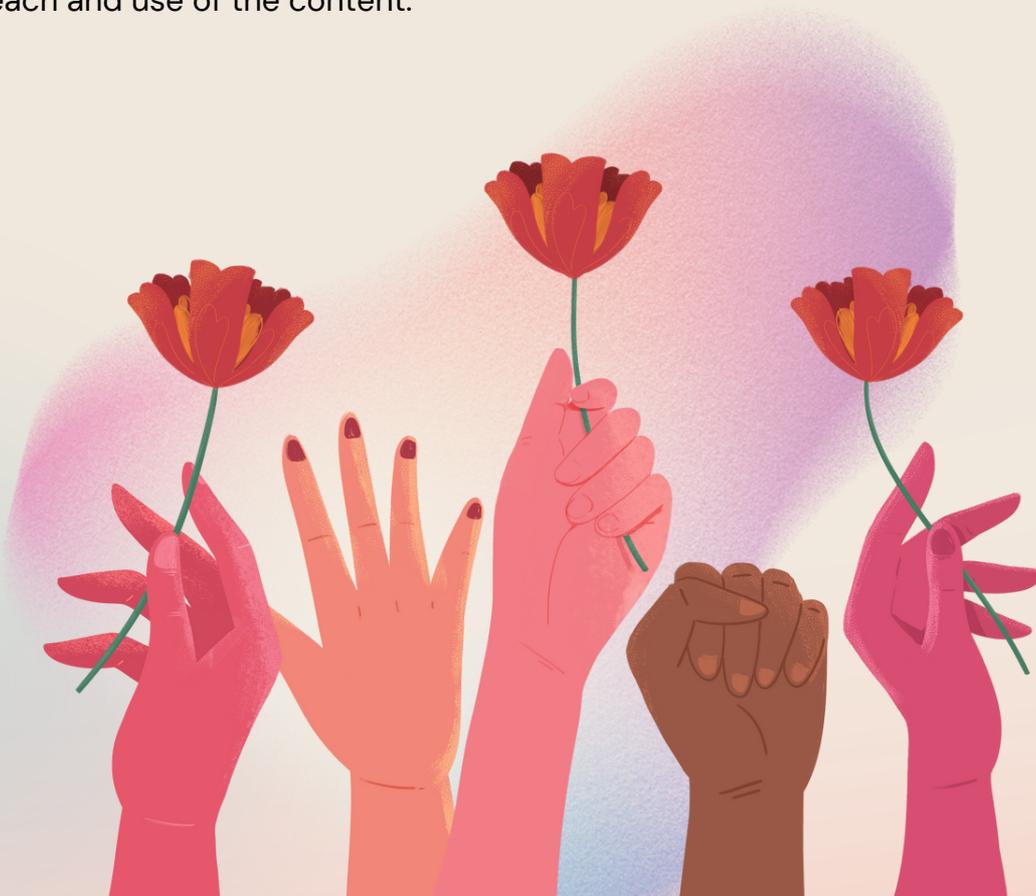
While these are not all women:

- 25 members of ASID – health, disability and research professionals, who attended the 1.5-hour training/webinar
- 14 members of AASW – social workers, who attended a 1.5-hour training/webinar
- 1000 people (national) who will receive the resources linked in our December 2022 newsletter, the Repro Wrap
- 165 contraception and abortion providers (130 practices, each with multiple staff) listed on our online Abortion and Contraception Provider Map (Queensland-specific) who will receive (in the next month) a direct email link to the resources
- 20+ Domestic and Family Violence and Sexual Assault Services and Disability services with relationships with partner organisations who will be directly contacted with resources and offers of support for implementation, in November 2022.
- Key stakeholder x 20 in leadership/sexual and reproductive health and rights roles in private and public health services in Queensland and Victoria who will be directly contacted with resources and offers of support for implementation, in November 2022.

Who benefits from these resources?

While it is too early to measure, our website has 500,000 visitors a year, and is where the resources will be freely available

- As per the grant application, there are 334,076 Australian women with intellectual and/or learning disabilities and their formal and informal support people, many of whom we hope will, over time and through word of mouth and strategic dissemination will gain access to the resources
- A range of academics who access the resulting peer-reviewed publication (still to be published), reach to be facilitated by open access publication, with funding to support this provided in the top-up grant we received, and in-kind by Children by Choice.
- The health professionals in the focus groups reported that they intend to use the resources with a range of client groups who have low levels of English literacy. They also described their intention to use the resources in training with other health and community sector professionals, expanding the intended reach of the resources and research outputs.
- The grant led to securing additional funds to translate the resources into 3 x short videos and printed 'take-home' booklets, which will further extend the reach and use of the content.



Feedback

Focus groups and webinars were used as an ongoing feedback loop throughout the duration of the project. 10 Hours of focus group data is undergoing qualitative analysis and will result in a wealth of feedback data that we will share with you in the coming months when the research manuscript has been finalised.

Some of the feedback shared with us via email by professionals who attended focus groups included:

"Thanks again for a wonderful session today. Very excited about these resources!"

-Professional focus group attendee - Manager, DV service

"Our team found we learnt a lot by simply being involved in the focus group. We learnt things from the resources themselves and from the other participants [health, disability and violence professionals] in the group who work in other specialities. It was also great to hear the feedback from consumers themselves, it was great timing that that consultation had already taken place before our focus group and Kari was able to share consumer thoughts. I imagine the resources could be very useful in one-on-one consultations in our sexual health clinic. We are also occasionally asked to present education to smaller groups of people with intellectual impairment. They would be very useful in that instance too."

- (Sexual Health Coordinator, Regional Sexual Health Service)

Feedback from women with intellectual and learning disabilities during focus groups included:

- *"Its good, great pictures"*
- *" A lot of people with disabilities don't know how they make their choices.'*
- *'People need to know what's ok and what's not'*
- *"Oh I didn't know you could go to a chemist to get tablets to stop any babies'*
- *'A lot of people don't know they are pregnant till it's too late'*
- *'Its good to help with these information sheets – people need to know'.*

“Its good to help with these information sheets – people need to know”

-Focus group participant

Focus groups acted as a continual feedback loop, as per co-design processes, throughout the duration of the project. Given the nature of the project, which focused on developing a series of resources, the appropriateness, accessibility and accuracy of resources was the primary measure of success, as well as the extent of participation and partnership.

Participants in the professional focus groups have further asked for resources in a range of formats so they can implement them into their group training with both professionals and women/clients.

Women with intellectual and learning disabilities and difficulties in the focus groups described how the resources will support them to have conversations about sex, contraception and coercive control with their own children and families.

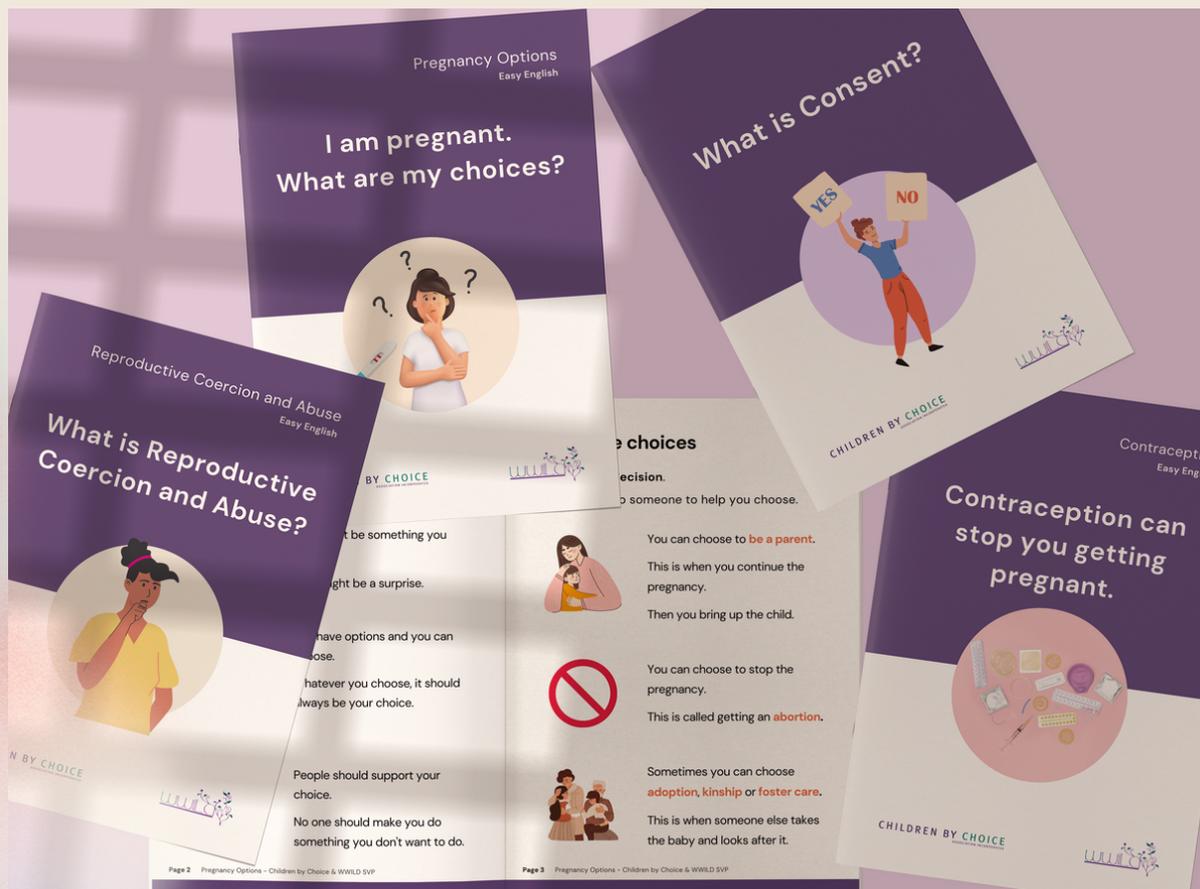
The project has also positioned WWILD SVP and Children by Choice as leaders in this space. The response from professionals to our ethical and participatory research and co-design practices has been praised and we were thus invited to present on process as well as outcomes, educating others in doing similar work and hopefully leading to increased engagement and representation of (the voices of) people with disabilities in sexual and reproductive health and rights policy, practice and research.

Next steps

As described, we are still in the final stages of printing and distributing resources and developing an 'instructions for use' guide to support a range of providers with a range of skill sets to use and distribute them appropriately and to maximum effect.

The additional grant we have received means we are now working to create new formats and hard-copy printed resources for distribution along with the printable resources. We are also generating 3 x short videos, as requested by focus group participants, and in doing so hiring a disability-focused acting company and videographer. This will further expand accessibility to the content to people with vision impairments and more significant disabilities, as well as others with low levels of English literacy.

The partnership with WWILD SVP and CbyC is thus ongoing, as research. Resource dissemination and video content creation activities remain, which wouldn't have been possible without the funding of 100 Women. We have learnt that this kind of ongoing collaboration is uncommon in our sector, as resourcing usually doesn't allow it.



Printed Resources & Videos

The primary objective of this project is to develop inclusive and suitable resources that can assist in educating people about reproductive coercion and abuse, pregnancy options, and contraceptive methods. Recent academic research has shown that accessible and interactive resources are more beneficial for participants, particularly those in ID communities (Traver et al., 2021). Therefore, our goal is to co-create resources with women and people with intellectual disabilities that address their unique pregnancy, contraceptive, and reproductive experiences. This will enable us to design a product that is respectful and sensitive to their needs.

Our main aim is to provide support to health professionals and sexual health providers to aid the communication with individuals with intellectual disabilities. These resources will support people with disabilities to learn about their sexual and reproductive health.

To achieve this goal, we have developed scripts and recorded videos featuring an actress, a counsellor and a doctor. These videos will provide additional audiovisual content to facilitate discussions and improve the understanding of people with intellectual disabilities when interacting with healthcare professionals.

Links to videos

[Contraception](#)

[Pregnancy Options](#)

[Reproductive Coercion and Abuse](#)



Learnings & recommendations

- Genuine partnership and co-design is expensive and slow. In future, we would ensure grants covered the cost of paying a member of the target population (such as a woman with an intellectual or learning disability or difficulty) to be on the project team more formally. We would ensure do our best to build in greater budget for more rounds of feedback in both co-design and research processes, and budget for specialty training to ensure project staff are as skilled as possible in delivering the outcomes. Completing this work as an 'in kind' contribution was crucial to ensuring the accessibility and accuracy of our final products.
- Building genuine organisational and individual partnerships is vital to true participation and true representation of the experiences and voices of key affected populations
- Systems, including universities and many grant processes, are not well set up to support inclusive research and co-design practices, as they often don't see value in the extensive, time-consuming collaborative processes that are critical to ensuring marginalised women's voices are centred in knowledge and service development activities. Furthermore, institutional systems and policies often shy away from or prevent work with marginalised women due to the 'risks' involved. Building genuine, ongoing partnerships is critical to the success of such work, and being willing to push-back against, and get creative, when faced with discriminatory systems and processes is vital.

Links to Resources

Pregnancy Options



I am pregnant.
What are my choices?



Contraception



Contraception can stop you getting pregnant.



Consent



What is Consent?



RCA



What is Reproductive Coercion and Abuse?



CHILDREN BY CHOICE

ASSOCIATION INCORPORATED

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