NSW Health Sexual Assault Services and New Street Services Access Strategy for People with Disability

Report on Needs Assessment

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Executive Summary

This needs assessment is the first stage in a project commissioned by the NSW Education Centre Against Violence (ECAV) to inform the design and implementation of the NSW Health Sexual Assault Services (SAS) & New Street Services Access Strategy for People with Disability (the Strategy) as part of NSW Health’s Integrated Prevention and Response to Violence, Abuse and Neglect Framework (the Framework). The needs assessment has been conducted to identify the evidence base to underpin the activities and implementation plan for the Strategy and its associated evaluation framework.

Aims, approach and context

The needs assessment aims to identify evidence-informed and promising practice and workforce initiatives that will support increased access to NSW Health specialist services for:

- children, young people and adults with disability who have experienced sexual assault and their families and carers, and
- children and young people who have engaged in problematic and/or harmful sexual behaviours.

It summarises evidence of the problem, identifies current barriers, gaps, opportunities, resources and initiatives, and identifies effective consumer participation models. From this evidence base, recommendations are made:

1. To improve service accessibility for
   - i. children, young people and adults with disability requiring NSW Health specialist therapeutic services in relation to sexual assault, and
   - ii. children and young people with disability who have engaged in problematic and/or harmful sexual behaviours

2. For consumer and stakeholder participation in the co-design stage of project and begin co-design capacity building with NSW Health.

While the content for these areas is presented in separate sections for clarity, given the intersections in service provision and practice the sections should be read together.

The needs assessment is built on an extensive review of the academic and grey literature, combined with individual and group interviews with 40 expert stakeholders. Themes from the literature review were used to scaffold questions for discussion in the interviews. Interviews were then used to confirm, challenge and build on the literature findings, with a focus on emerging and promising practices, strategies for inclusive services, and identified gaps and barriers in services. Participants in the interviews were also asked to discuss their experience of co-design and co-production, to inform the co-design process and the activities and implementation plan to support existing services to improve service accessibility for people with disability.

The context of developing the needs assessment includes how we think about disability and the intersection between disability, violence, abuse, neglect and exploitation.

Statistics indicate people with disability of all ages are disproportionately likely to experience sexual violence than people without disability, although these figures are undoubtedly an underrepresentation. There is little evidence about prevalence of children and young people with disability who have engaged in problematic or harmful sexual behaviours. The literature cautions against conflating children and young people with disability together with problematic and harmful sexual behaviours. It is also important to note that children and young people who have engaged in

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\(^1\) People who experienced violence since they were 15, women with disability 25%, women without disability 15%, men with disability 6.5%, men without disability 3.9% (Personal Safety Survey 2016 in Australian Institute of Health and Welfare, 2019)
problematic and/or harmful sexual behaviours are also often victims of sexual violence themselves, and other forms of domestic violence, physical abuse and neglect.\(^2\)

Over the last decade, numerous inquiries and royal commissions into the treatment of people with disability have heightened the focus on violence and abuse. These inquiries identify important recurrent themes, which include activating the human rights of people with disability; meaningfully including people with disability in mainstream violence policy and practice responses; addressing the siloed approach to policy and service provision to better address violence prevention and response; and developing useful practice to support people with disability who experience violence and abuse.

The Royal Commission into Institutional Responses to Child Sexual Abuse made many recommendations, and these underpin the need for addressing the issue of service support for people with disability who have been victims of sexual abuse and violence and children and young people with disability who have engaged in problematic and/or harmful sexualised behaviour.\(^3\) The current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is due to hand down its final report in 2022.

The policy context is the NSW Health Integrated Prevention and Response to Violence, Abuse and Neglect Framework (IPARVAN) framework that seeks to strengthen NSW Health services in responding to violence, abuse and neglect in NSW, and maps the need for change and a public health approach to Government reform to ensure people in NSW live free from violence.\(^4\) The framework highlights an intersectional approach and identifies people with disability as one of the priority population groups.\(^5\)

The practice context is that referral rates for services are significantly below the estimated prevalence rates for sexual violence among people with disability.\(^6\) ECAV offers a suite of training across a range of areas focused on violence and is committed to further embedding co-design principles and practice into training and other work with people with disability and to build on existing practice.

**Evidence for improving accessibility**

Clear evidence of practice principles to guide service provision emerged from the literature and the interviews. There are eight practice principles which underly service approaches and underpin positive practices.

**Activating a human rights-based approach**

Rights-based approaches include, participation - people with disability have the right to participate in all decisions affecting them; accountability - where services are accountable, monitored and compliant with human rights; and non-discrimination, where people who are marginalised and vulnerable are supported to access their rights as citizens.\(^7\) Expert knowledge from people with disability also underpins a human-rights based approach to service provision.

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\(^2\) Hackett, Branigan, & Holmes, 2019; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020

\(^3\) Breckenridge & Flax, 2016; Llewellyn, Wayland, & Marsh, 2016; Quadara et al., 2017; Robinson, 2016

\(^4\) NSW Ministry of Health, 2019, p. 3

\(^5\) NSW Ministry of Health, 2019, The Case for change, p. 23-25

\(^6\) Priority population’ is a term used to refer to diverse groups for whom there is significant evidence of heightened vulnerability to violence, both in frequency and severity, and who may encounter a range of specific barriers to seeking support and securing safety, related to intersecting identity-based and situational factors and experiences of discrimination. While a range of terminology is used by and to describe these groups, ‘priority population’ is consistent with the NSW and national policy landscape (Council of Australian Governments, 2011; Centre for Epidemiology and Evidence, 2018)

\(^7\) ECAV project brief, 2020

Improving access and accessibility

Access can be thought of as ‘I have access to’, and accessibility as ‘it is usable to me’. Access refers to the availability of appropriate services with capacity that are located within a reasonable geographic distance. This includes timely access to assessments and services, and service reviews. Accessibility describes the nature of services – the way services are designed; how they are adapted and adjusted in a flexible way, and how they acknowledge and respond to diversity in disability populations.

Recognising and responding to barriers

People with disability face entrenched barriers to accessing services when they experience sexual violence, including being believed and listened to by people they disclose to, ongoing safety and security, and having their legal and human rights respected in their daily lives. Challenges in accessing services centre around recognising and responding to these barriers. Studies have systematically noted barriers to services also include recognition of violence in the lives of people with disability, attitudes toward people with disability, and the impacts of siloed service delivery, which fails on multiple levels to address people’s needs.

Countering discriminatory attitudes

Long-standing discriminatory attitudes toward people with disability, and negative community attitudes about their sex and sexuality, education and rights are frequently identified across the literature. These attitudes from families, workers and the broader community, commonly view people with disability as non-sexual, hyper-sexual or inappropriately sexual. These stereotyped and inaccurate views are pervasive, and impact on both the victim-survivor’s capacity to disclose, and the responses by others to that disclosure.

Recognising and responding to capabilities

Strength-based approaches have a strong and well-established evidence base across multiple fields. In the face of other evidence about the weight of negative experience and the effects of discrimination, recognising and responding to capability in people with disability is especially important. This includes recognising that people with disability employ patterns of resistance, resilience and demonstrate other strengths to maintain their safety.

Taking a holistic approach

The literature identifies a holistic approach as a key principle when working with and supporting victim-survivors of sexual violence. Holistic approaches build on strengths-based and individual capabilities, respond to the individual and recognise intersectionality and the diversity of disability experience. A holistic approach responds to people’s broad health and wellbeing needs, including housing, financial support, cultural support, medical care, mental health or drug and alcohol support, etc. There is strong evidence in research and practice that responding to people’s needs reduces risk of violence and abuse and contributes to safety and wellbeing.

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8 (Robinson, Frawley & Dyson, 2020)
9 (Barrett & Pierre, 2011; Mandl et al., 2014)
10 (Maher et al 2018)
11 (Maher et al 2018)
12 (Dowse et al 2013; Dyson et al, 2017; Maher et al 2018)
13 One participant (policy maker) noted that this attitude is evidenced by the High Court challenge by the Government against providing sex work services in NDIS funding.
14 (Olsen & Carter, 2016)
15 (Ballan & Freyer, 2012; Olsen & Carter, 2016; Sammet Moring, Parish, Mitra, & Alterio, 2019)
16 (Douglas & Harpur, 2016)
17 (Franklin, Bradley, & Brady, 2019, p. 18)
18 (Barrett & Pierre, 2011)
19 (Maher, 2018, Robinson et al, 2020a)
Using trauma informed approaches

Recent research recommends the need to ‘embed trauma informed care within a holistic wellbeing framework that integrates mental, physical and psycho-social wellbeing’. The literature on trauma-informed practice with people with intellectual disability is consistent with well-regarded practice frameworks, emphasising that re-traumatisation can occur without the essential principles of safety, trustworthiness, choice, collaboration, and empowerment, cultural, historical and gender issues.

Applying an intersectional lens

While intersectionality is derived from the effects of gender and race, it helps in understanding how people live ‘on multiple axes of oppression simultaneously’, including, race, gender, disability, social identity and difference. An intersectional lens is productive for thinking about disability and sexual violence, where forms of discrimination and disadvantage based on people’s multiple identities can increase the severity and frequency of sexual violence and barriers to support.

Practices for improving accessibility in sexual assault services

The eight principles underpin the positive practice identified in the literature and across the interviews with stakeholders. Accessibility to services is conceptualised through pathways and effective services.

Effective pathways, referrals and access

Effective pathways are facilitated through accessible information, a person’s capacity and opportunity to disclose experiences of sexual violence, and timely and appropriate referrals. Appropriate support is accessible in all senses of the term, publicly well-known, easy to find and participate in, with victim-survivors confident they will be safe following disclosure. Successful pathways depend upon a set of non-sequential events.

Firstly, understanding, knowledge and attitudes about sexual violence signal that people with disability and their carers/family members, community members and peer networks recognise or identify sexual violence. This includes education that helps shift community attitudes about sexual assault and increases awareness of the dynamics that get in the way of victims disclosing.

Secondly, people within their network need to understand disclosure which may come about through direct or indirect means, or via emergency/crisis interventions in a crisis.

Appropriate referrals follow disclosure and depend on the person who learns of the sexual violence to take responsibility to support the person with disability to access services. Referrals are also dependent on people (person themselves, family, friends or person disclosed to) finding out accurate information about service options, along with the availability of accessible, knowledgeable services to receive the person. Referral pathways should be accessible, publicly known, easy to find and participate in, and safe (confidential, culturally, emotionally and physically). Information should be accessible with multiple and adapted formats. Service pathways should respond to the needs of the whole person.

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20 (Franklin & Smeaton, 2017; Salter et al., 2020)
21 (Jackson & Waters, 2015)
22 (Gardiner, Larocci, & Moretti, 2017; Kezelman & Stavropolous, 2019; Substance Abuse and Mental Health Services Administration, 2014)
23 (Crenshaw, 1991)
24 (Robinson, valentine, et al., 2020, p. 4; Shaw, Chan, & McMahon, 2012; Stubbs, 2015)
25 (Costello & Backhouse 2019)
26 (Dyson et al., 2017; Mandl et al., 2014; People with Disability Australia & Domestic Violence NSW, 2015)
27 (NSW Government PD2020_006 p221)
28 (Field, 2017)
29 (Carswell, Donovan, & Kawai, 2019)
30 (Allnock et al., 2012; Women with Disabilities Australia (WWDA), 2016)
31 (Banks, Kelly, Kyegombe, Kuper, & Devries, 2017; Fraser-Barbour, 2018; Frawley et al., 2015)
Effective sexual assault services and support for people with disability

The literature outlines a range of effective practices in services for people with disability who have experienced sexual violence, although evaluation of programs is limited. Sexual violence frequently co-exists with other forms of abuse, domestic violence, neglect and exploitation. The impact of sexual violence across victim-survivors’ life domains highlights the need for collaborative and interagency service response, with methods adapted to building on a person’s strengths and abilities through person-centred approaches, which are key to support people with disability.

The literature outlined the following conditions that facilitate positive and effective practices, which are underpinned by the principles noted earlier, and respond to diverse needs of disability and intersectionality of the victim-survivor. Stakeholders views reinforced the findings of the literature.

Effective services and support for people with disability who have experienced sexual violence:

1. Are accessible: in attitudes, information and practices, and open to diversity in disability. This includes flexibility, time, communication supports and care-coordination.
2. Are relationship-based: the victim-survivor’s needs are at the centre (person-centred, strengths-based) of service responses and include family support. Service responses are confidential, and culturally, emotionally and physically safe, and use supported decision-making.
3. Draw on expert knowledge from people with disability, especially women and girls.
4. Use multisector collaboration and information sharing to accommodate the person’s needs.
5. Are flexible – in approach, time, service location and outreach (and capacity).
6. Build their workforce: staff have appropriate training, capacity (availability) and competency (and confidence) and are diverse and skilled.

Practices for improving accessibility in services for children and young people with disability who have engaged in problematic and/or harmful sexual behaviour and their families

Interventions for children and young people who have engaged in problematic and/or harmful sexual behaviours require a holistic approach to address the harmful behaviours together with factors that increase their vulnerability to harm. Along with early intervention and proportionate response to behaviours, the evidence highlights prevention of harm as an intrinsic part of service support.

Pathways, referral and access to support

Support, referral and access pathways for children and young people who have engaged in problematic and/or harmful sexual behaviours rely on someone recognising or understanding these behaviours, disclosure by the victim or witness and help-seeking or referral by families, schools or others. Identifying and responding to problematic and/or harmful sexual behaviours presents

32 (Lund, 2011)
33 (Douglas & Harpur, 2016; Franklin et al., 2019; Jessiman & Carpenter, 2018; Robinson et al, 2020b)
34 (Jessiman & Carpenter, 2018)
35 (Jessiman & Carpenter, 2018; Mandl et al., 2014; Olsen, Majeed-Ariis, Teniola, & White, 2017, p. 244; Robinson et al., 2020 b)
36 (Frawley et al., 2015; Robinson et al., 2020a)
37 (Ballan & Freyer, 2012; Cripps et al., 2010; Franklin & Smeaton, 2017; Fraser-Barbour, 2018; Frawley & Anderson, 2014 ; Jessiman & Carpenter, 2018; McGilloway et al., 2020)
38 (Fraser, Hackett, Masson, & Phillips, 2019)
40 (Balfe, Hackett, Masson, & Phillips, 2019 ; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
challenges for families, communities, and people working with children, particularly when the child or young person has intellectual disability. Stakeholders argue for improved education across the community, around issues of harmful sexual behaviours and sexual violence, sexuality and sex education for children and young people with disability and other preventative approaches such as developing healthy relationships, managing bullying and social inclusion. Stakeholders noted an increased need for education for all.

The literature suggests a framework for accessing supports including referrals is integral to effective management and support of children and young people who have engaged in problematic and/or harmful sexual behaviours. In the interviews stakeholders noted referrals increased with knowledge of services and when professionals, families and others working with children were made aware of a service. This may occur through community contact and program visibility, close collaborative working relationships, integration with other children’s services and in some instances through co-location as is the case in under 10 regional and rural Community Health Services. Access to timely support was often negatively impacted by lack of local services in rural and remote areas.

**Effective services and support**

The literature emphasizes that children and young people who have engaged in problematic and/or harmful sexual behaviours are children first; and states the importance of tailored responses to harmful sexual behaviours, that are person-centred, relationship-based and address the child’s life domains. Children and young people who have engaged in problematic and/or harmful sexual behaviours often have complex needs and those with disability require specific interventions based on their needs and additional vulnerabilities.

Stakeholders emphasised the importance of looking beyond static descriptions of ‘vulnerability’ or ‘risk factors’ which are focused on deficits in children, and focus on the integration of the young person’s strengths and needs, family and carer support, and collaborative work across services to reinforce behaviour change. There is a need for interagency and holistic responses to address gaps and shortfalls which left children lacking effective support. Adapted methods need to accommodate the capabilities, understanding and capacities of the young person and benefit from ‘effective collaborations between clinical professional and the individual’s support carers/family members, community members and peer networks. Resources can also be adapted to suit the capabilities of the young person, such as scaffolding information, using pictures or other modes of communicating, cartooning, developing emotional regulation, social storying and other social skills including prompting.

Practices for improving accessibility in services for children and young people with disability who have engaged in problematic and/or harmful sexual behaviour and their families:

1. Strengths based, timely and proportionate responses, including person-centred and relationship-based responses. This includes developmentally and culturally appropriate programs, which include safety plans for children to prevent future harmful behaviours and who may be at risk. Holistic and trauma informed responses that recognise children and young people often have other traumatic events in their lives.
2. Multi-modal approach to support children and their families, developing parent/guardian support and skills.
3. Multiagency partnerships and collaborations.

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42 (KPMG, 2014)
43 (Hackett et al., 2019 p. 39)
44 (Balfe et al., 2019)
45 (Hackett, Phillips, et al., 2013)
46 (Keller, 2016)
47 (Bateman & Milner, 2014)
48 (Bateman & Milner, 2014)
49 (Hackett et al., 2019; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
50 (Keller, 2016; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
4. Education and training to improve and develop workforce skills in trauma informed practices, working with children and young people with disability and their families.

**Co-design and co-production**

Co-design is framed optimistically as a process for governments and service providers to work with communities and service users in a more equal partnership and dynamic relationship to understand issues and create knowledge for change. Co-design is a process that can produce different knowledges and lead to social transformation. Underlying co-design are principles to ensure meaningful citizen engagement between stakeholders and the assumption that the ‘provider and user can work actively together in the delivery of a service’.

There are six principles of co-design and co-production.

1. Power sharing – projects acknowledge and manage power differences, share responsibility, and have methods in place to ensure shared responsibility and collective control and ownership of the project.
2. Diversity – different expertise and skills are brought together and all voices are respected and valued.
3. Accessibility – barriers that prevent participation are addressed and including physical and information accessibility.
4. Reciprocity – co-production is mutually beneficial for all participants and stakeholders.
5. Transparency – there is a shared understanding of the goal of the co-production, and recognition of each participant’s skills, with open communication that builds trust in relationships.
6. Flexibility – co-production needs to adjust to the participant’s needs, skills and resources.

Consumer representatives and other stakeholders articulated clear advice about co-design that reinforce the findings from the literature. Consumer representatives also emphasised that inclusive co-production values building relationships and rapport; developing a shared language and communication protocols that are accessible; facilitating participation through training for all participants, including disability supports; tailoring responses and support to the diverse needs of participants: and listening to people with disability across the community.

Challenges to co-design and production include a dependence on text-based information, not accommodating the diversity of worldviews, and misunderstanding around shared goals and expectations.

**Recommendations**

The project recommendations aim to activate the principles and practices identified in this literature review and stakeholder interviews. These are pitched at a level to initiate change in practices and are also threaded to the practice principles for accessible services in section 3 of the report. Recommendations also connect directly to the implications for training, resource development and collaborative approaches identified in the evidence (summarised in the Appendix).

In addition, a series of key priorities for improving access for training delivery, resource development and organisational support are identified to improve practice for workers, organisations and across sectors. These are detailed in the full report.

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51 (Beebeejaun, Durose, Rees, Richardson, & Richardson, 2014)
52 (Beebeejaun et al., 2014)
53 (Crompton, 2018)
54 (Strnadova, Dowse, & Watfern, 2020)
1. **ECAV role in improving integrated cross sector collaboration**

By virtue of its position as a trusted education provider with existing collaborative relationships with other key central NSW Health organisations including the Health Education and Training Institute (HETI) and Agency for Clinical Innovation (ACI), ECAV can play a valuable role in improving integrated service delivery between NSW Health Sexual Assault Services, New Street Services and wider VAN Services.

ECAV can promote and support more effective cross sector collaboration between NSW Health Sexual Assault Services and New Street Services and disability sectors to improve the use of sexual assault services by people with disability. These collaborations would focus on providing a holistic strategy approach for children, young people and adults with disability and include referral pathways (in a ‘no wrong door’ approach\(^{55}\)), therapeutic interventions, addressing housing, financial support, cultural support, medical care, mental health or drug and alcohol support etc.

ECAV can lead solutions to breaking down siloed services through delivery of localised integrated and interagency training opportunities that will enhance knowledge of existing services and referral pathways. Offering education and training outside of the sexual assault sector is one strategy to open the door to collaboration. Knowledge of the composition of workforce and service user populations can inform priorities for ECAV when targeting training opportunities.

Another is to build communities of practice which invite multi-disciplinary collaboration across the range of domains where people with disability commonly interact, including education, health, justice, and specialist services such as NDIS and disability support agencies.

2. **Promoting disability inclusive service design**

Statistics from the prevalence data suggests there is a high likelihood that person with disability ‘should’ present to sexual assault services. However, we know that they don’t; not because they don’t experience sexual violence etc, but because they are frequently an afterthought in service design and therefore services are not inherently inclusive of their needs. Several key issues emerge from this:

- Encouraging and supporting inclusive service design assumes disability in potential clients rather than considering it an ‘exception’ – and this can lead to fundamental design principles that benefit all clients and lead to ‘disability-ready’ services.

- Service design thinking\(^{56}\) is a very useful framing for reconceptualising approaches to build inclusive services. The five principles of the framework are that services are user centred; co-creative; sequenced; evidenced; and holistic.

We recommend ECAV incorporate inclusive service design thinking into training for managers of sexual violence services to support and encourage co-design with people with disability; lateral thinking about creating inclusive environments; generate a holistic approach that avoids diagnostic approaches to disability; embed consideration of accessible service engagement, clinical outreach and resource use from the outset; develop responsive and strength based clinical practices and respond to localised priorities.

3. **Embedding co-design**

ECAV has a 30-year history of embedding co-design principles into their work with Aboriginal communities through the long-term establishment of an Aboriginal Communities Matter Advisory Group and Aboriginal Training Portfolio that develops and delivers state-wide community and worker programs. ECAV also applies community-based participatory research methodology to related violence projects established to develop practice-based evidence through close collaboration with people with lived experience and relevant practitioners. This knowledge and experience can be leveraged and its principles applied to its future work with people with disability.

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\(^{56}\) (Stickdorn, & Schneider, 2012)
There are strong opportunities in this project to work in collaboration with people with disability, together with the disability and sexual assault sectors (sexual assault services and services for children and young people with problematic and/or harmful sexual behaviours). Opportunities are facilitated through these approaches:

- Co-designing foundational training, ongoing professional development and an effective supervision model.
- Co-designing resource development for children, young people and adults with disability and their families and carers; as well as the disability and sexual assault harmful sexual behaviours sectors.
- Co-designing the development of communities of practice, through state-wide practice forums and roundtables to build and strengthen capacity within Sexual Assault, New Street and wider VAN workforces.
- All initiatives are to embed the leadership of people with disability (for example, consumer-led governance models, consumer co-facilitation and consumer involved supervision).

We recommend ECAV establish a Co-design working group with at least three disabled people’s (peer-led) organisations partnered in this project to develop a Co-design Framework and consider the value of an accessibility audit tool for sexual violence and harmful sexual behaviour services. Other relevant stakeholders should be included as appropriate. Their role will be to advise, critique and strengthen co-design principles and practices; consider potential from the work in practice for the disability context; and build on existing practice in disability training, resource development and collaboration.

4. **Education for leadership and collaboration**

This needs assessment demonstrates that education to develop leadership capability is needed to drive change across sexual assault and harmful sexual behaviour services. ECAV should give consideration to developing a leadership development program to build workforce leadership for NSW Health SAS and NS Services around disability inclusive practice in the following areas:

- Building state-wide and local partnerships with disability providers/peak bodies
- Driving NSW Health and interagency policy reform
- Promoting and supporting staff to improve skills and engage in flexible clinical outreach
- Engagement and counselling with people with disability
- Establishing and encouraging ongoing supervision and peer support to develop and contribute to practice informed evidence in this area
- Implementing co-design framework and audit tool within VAN services and across LHDs/Networks.

5. **Building and maintaining high quality resources**

Making resources accessible to people with a diverse range of disabilities is essential for accessible service provision. A wide selection of resources has been developed about violence and sexual violence for people with disability. These vary significantly in quality and availability. One substantial barrier is reliability of access to resources – when project funding finishes, so does access to resources.

- Establish an accessible Information and Resource Database under the ECAV Disability and Sexual Violence Information and Resources Databases online sharepoint
- Ensure easy read, multi-language and accessible to screen-reader online formats
- Undertake an audit of existing resources and consult with consumers and stakeholders to determine gaps and future development of useful resources: e.g. supported (warm) referral, how to persist in getting what you need, managing your feelings, getting support from workers and your own networks at the same time
6. **Visibility of services and expertise within the sector and across the community**
   - Develop promotional material to help sexual assault services explain their role and what they offer in an accessible format for people with disability
   - Develop community education resources for sexual assault and harmful sexual behaviours services and disability providers to partner in raising awareness of sexual assault and harmful sexual behaviours to increase engagement with disability community
   - Consider developing a matrix which local services can adapt to develop pathways to support for all sectors (a local ‘no wrong door’ approach)
   - Build capacity for disability providers to identify and respond effectively to sexual violence
   - Build capacity for Sexual Assault and New Street services to deliver clinical outreach and effective community engagement strategies with disability communities
   - Build capacity and provide training for workers to understand and work with existing frameworks about information sharing across sectors.

7. **Evaluation**
   
   Ongoing and systematic evaluation of services support the development of evidence-based practices. Evaluation is key to maintaining positive practices that reflect the needs of people with disability and children and young people who have engaged in problematic and/or harmful sexual behaviours. The literature notes a lack of systematic evaluation in this field and has long supported the need to capture and use data to implement positive change and develop services. Inclusive evaluation of the ECAV project which meaningfully involves all stakeholders, including people with disability, will be important in effectively measuring depth and quality in initiatives. An evaluation framework is part of the next phase of ECAV’s work.

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57 (Didi et al., 2016)
Part I: Aims, approach and context

1. About the project

1.1 Aims

This needs assessment is the first stage in a project commissioned by the NSW Education Centre Against Violence (ECAV) to inform the design and implementation of the NSW Health Sexual Assault Services (SAS) & New Street Services Access Strategy for People with Disability (the Strategy) as part of NSW Health’s Integrated Prevention and Response to Violence, Abuse and Neglect Framework (the Framework). The needs assessment has been conducted to identify the evidence base to underpin the activities and implementation plan for the Strategy and its associated evaluation framework.

The needs assessment aims to identify evidence-informed and promising practice and workforce initiatives that will support increased access to NSW Health specialist services for:

- children, young people and adults with disability who have experienced sexual assault and their families and carers, and
- children and young people who have engaged in problematic and/or harmful sexualised behaviours.

It summarises evidence of the problem, identifies current barriers, gaps, opportunities, resources and initiatives, and identifies effective consumer participation models. This evidence base is confirmed and extended, and emerging and promising practice identified through targeted interviews with consumers, service providers, policy makers, consumer bodies and academics. This does not include a clinical level discourse about counselling techniques.

A series of implications for improving access through identifying key priorities in organisational support, training delivery and resource development are drawn from the evidence and consultations. For clarity, these are provided in succinct call-out boxes entitled key priorities for improving access, at the end of each sub-section, as well as collated in the Appendix.

From this evidence base, recommendations are made:

1. To improve service accessibility for
   a. children, young people and adults with disability requiring NSW Health specialist therapeutic services in relation to sexual assault, and
   b. children and young people with disability who have engaged in problematic and/or harmful sexualised behaviours

2. For consumer and stakeholder participation in the co-design stage of project and begin co-design capacity building with NSW Health.

While the content for these areas is presented in separate sections for clarity, given the intersections in service provision and practice the sections should be read together.
1.2 Structure of this report

The report is structured in four parts:

Part I: Aims, approach and context

- **Section 1** outlines the aims and approach of the project and structure of the report
- **Section 2** describes the policy and practice context for the issue and current barriers and gaps to effective practice.

Part II: Evidence for improving accessibility

- **Section 3** outlines key practice principles for effective services developed from the evidence in the literature and interviews
- Drawing from the research evidence and insights from key stakeholders, sections 4 and 5 describe positive practice, barriers and a range of opportunities and existing resources and initiatives for building accessibility.
- **Section 4** details specific findings for improving practice in sexual assault services.
- **Section 5** draws out specific findings for improving accessibility of services for children with disability who have engaged in problematic and/or harmful sexualised behaviours.

Key priorities for improving access are highlighted at the end of each sub-section.

Part III: Co-design and co-production

- **Section 6** outlines principles of co-design and co-production methods for developing the evaluation framework and implications for building workforce capacity.

Part IV: Recommendations

- **Section 7** provides recommendations for improving service accessibility for people with disability requiring NSW Health specialist therapeutic services in relation to sexual assault and children and young people with disability who have engaged in problematic and/or harmful sexual behaviours.

Part V Appendices include a summary of implications for key priorities to improve access; a table of useful resources for practice identified during the project; a reference list, the interview discussion and feedback form, and a glossary of terms used in the report.

1.3 Approach

The needs assessment is based on extensive review of the academic and grey literature, combined with individual and group interviews with expert stakeholders. Themes from the literature review were used to scaffold questions for discussion in the interviews. Interviews were then used to confirm, challenge and build on the literature findings, with a focus on emerging and promising practices, strategies for inclusive services, and identified gaps and barriers in services.

Participants in the interviews were also asked to discuss their experience of co-design and co-production, to inform the co-design process and the activities and implementation plan (contained within the SAS and NS Access Strategy for People with Disability) to support existing services (SAS and NS) to improve service accessibility for people with disability.

The research study has ethics approval from the Human Research Ethics Committee at the University of New South Wales (HC 200144). Flinders University Social and Behavioural Research Ethics Committee ratified the UNSW ethics approval (OH-00249).

1.3.1 Academic literature searches

Databases for academic literature searches included: CINAHL, Scopus, Proquest, Informit (APAFT), Wiley online and Google Scholar. Search mechanisms in databases vary and this can impact on search consistency. Searches were modified to capture key literature across all databases.
Search terms used to screen titles and abstracts included - disability, sexual violence (including abuse, rape, assault), programs (interventions, responses, barriers) and children and young people OR adults and women with and without ‘harmful sexual behaviour’. Sources published between 2010 and 2020 were included in the search in order to capture the most up to date evidence in the field.

All initial 617 references (without duplicates) were subject to Title and Abstract screening in the program Covidence. This screening established usefulness of the article to the project scope, full text availability and time validity. Following the first screen 207 articles of relevance were identified. A second screen was conducted by a second moderator. In this screening articles addressing offenders and harmful sexual behaviour without reference to people with disability were discussed and excluded.

At completion of the moderated Title and Abstract screening 128 articles were deemed relevant to the study. These articles identified topics relevant to the needs assessment regarding sexual assault services and services for children and young people with problematic or harmful sexual behaviours, listed here in alphabetical order:

- Harmful sexual behaviours
- Impacts of sexual violence, abuse or assault
- Interventions and barriers to support and services for people with disability or general population
- Prevalence of experiences of sexual abuse violence among populations with disability.
- Programs focusing on prevention and education

1.3.2 Grey literature searches

Searches of grey literature included federal and state policy, strategy, framework and action documents publicly available and resources and research from institutional research centres and advocacy organisations. The ECAV Project Committee also provided advice on key sources. Overall, the grey literature searched included:

- Government documents, including strategy, implementation and strategy documents where available from: Commonwealth Government, New South Wales, Victoria, South Australia, Queensland, Western Australia, Northern Territory, Tasmania, Australian Capital Territory
- Royal Commission into Institutional Responses to Child Sexual Abuse, final report, research reports
- ANROWS
- Our Watch
- Systemic advocacy and disability organisations
- Key family, violence, and disability research centres (Australia and international)

1.3.3 Interviews with stakeholders

Participants were identified by the project team (Flinders University and University of New South Wales) in consultation and with recommendations from ECAV. Interviews with individuals or groups were held with:

- policy makers in health, disability, mental health, and safeguarding domains,
- service providers in disability and sexual assault services,
- peak and systemic advocacy organisations with specialist content knowledge in violence and disability,
- disability advocacy and consumer representative groups; and
- academics and researchers.
The interviews were held during COVID-19 lockdown, necessitating a distanced approach. Interviews were held online or by telephone in group or individual interviews. This approach allowed for flexibility and made it possible to interview different stakeholders together across time zones, states, and sectors. Stakeholders were both within and outside NSW. Group interviews brought together people with similar and contrasting work experiences, which allowed for discussion of shared and different views. The project team was provided with additional information, feedback and recommendations from members of the NSW Health Sexual Assault & Disability Access Project Committee. Despite flexibility for participation through online interviews for some people with disability, conducting interviews online reduced accessibility.

Fifteen interviews were held with a total of 40 participants ranging in duration from one to two hours, with an average of one and half hours. In keeping with NSW and Flinders ethics protocols information about individual participant’s roles are confidential. In keeping with the project brief, stakeholders were consulted representing Aboriginal, CALD, mental health, intellectual disability, justice interface, and consumer peak perspectives.

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Range</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer groups</td>
<td>Representatives of six Disabled People’s Organisations (organisations led by people with disability)</td>
<td>13</td>
</tr>
<tr>
<td>Service providers</td>
<td>Disability&lt;br&gt;Disability and sexual assault&lt;br&gt;Problematic and harmful sexual behaviours&lt;br&gt;Sexual assault&lt;br&gt;Sexual assault and Problematic and Harmful Sexual Behaviours</td>
<td>16</td>
</tr>
<tr>
<td>Policy makers</td>
<td>Policy makers, including specialist intellectual disability and health, disability services and justice, intellectual disability and mental health, Sexual assault services policy Disability and Sexual Assault Services policy Disability policy</td>
<td>9</td>
</tr>
<tr>
<td>Academics</td>
<td>Inclusive disability researchers</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 1 Interview participants

Prior to interviews, participants were provided with information forms about the study, and were required to sign a consent form or provide verbal consent to participate. Participants who agreed to take part were sent a discussion guide with focus questions developed from the key themes from the literature review (appended). The interviews focused on applying and extending what is known from the literature and facilitating new learning for the project team about current practice. The interviews addressed questions of positive and effective practices in sexual assault services for people with disability, and support services for children and young people with disability who have engaged in problematic or harmful sexual behaviours. Participants were asked to provide examples of practice. Following the interview each participant was sent a follow up email if they wished to provide additional information (appended).

As part of the consultation process, two group interviews were held with peer-led advocacy groups. For ethical reasons, these groups used less direct questioning with people with disability about this sensitive topic, and these discussions focused on positive help-seeking experiences and asked about positive and negative experiences when engaging with support or other services.
2. Context for the issue

2.1 Approaches to disability

Our understanding of disability draws on the United Nations definition:

Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.\(^{58}\)

The term ‘people with disability’ is used throughout this report to refer to a population group who experience impairment and who are known to face barriers to equal inclusion to many services, including those that they need in times of crisis. However, people with disability make up around 20% of the population.\(^{59}\) The NSW population of people with disability reflects this. Of the 7.8 million residents of NSW in 2015, 18.3% or 1.37 million people identified as people with disability.\(^{60}\)

Of these people:

- 78% have a physical condition (including acquired brain injury, arthritis, asthma, multiple sclerosis, spinal cord injury and stroke)
- 20% have ‘mental or behavioural disorders’ (note this is not a preferred term by people with disability)
- 6% have been diagnosed with intellectual disability
- 7.4% have been diagnosed with psychoses and mood affective disorders (including dementia, depression)

Around a third of people with disability in NSW have ‘severe or profound core activity limitations’ which restrict everyday activities relating to self-care, education, employment, community participation and mobility. Almost half of people with disability have a moderate activity limitation in relation to schooling or employment. Twenty-two percent of people require mobility assistance\(^{61}\).

Twenty percent of people with disability in NSW have a primary carer. Carers include partners (39%), parents (22%) and children (no figures available). A third of primary carers themselves have disability.

Poverty impacts many people with disability in NSW. The median gross weekly wage of working people with disability is slightly under half of that of people without disability.\(^{62}\) Fifty five percent of people with disability are reliant on a government benefit or pension as their primary source of income. People with disability have additional living costs associated with their disability which are not well covered by government benefits.

This is a highly diverse group – ranging from people who face few barriers to people who need support for every part of their lives. Some people may come into contact with sexual assault services because one terrible event happens in an otherwise flourishing life. Others are entrenched in disadvantage, and sexual violence is one part of various forms of violence, abuse, neglect and exploitation.

It is helpful to think about how *impairment* (conditions, injuries and illnesses experienced by people) intersects with *disability* (the physical, social and structural barriers that affect inclusion and citizenship). This is the social model of disability.\(^{63}\) Disability is a ‘complex phenomenon,
reflecting the interaction between features of a person’s body and features of the society in which he or she lives.\(^6^4\)

Culture overlays approaches to disability, and it is important to be aware that people from culturally diverse backgrounds and Aboriginal people can have diverse understandings of disability, ranging from shame and stigmatising views in some conservative communities through to inclusive Aboriginal approaches which take a collectivising view of disability as a holistic part of a person’s identity. Equally important is the need not to make assumptions that people from diverse backgrounds hold particular views on disability and impairment.

Disability is one part of people’s lives, but when people face resistant barriers, the impact of disability is magnified. This demonstrates the importance of improving the accessibility of services which are designed to support people at difficult times in their lives.

### 2.2 Sexual violence in the context of abuse, neglect and exploitation

As noted above, sexual violence is more likely to be a pattern of abuse rather than a one-off incident, and often coexists alongside other forms of prolonged abuse such as child abuse and neglect, domestic violence and exploitation. This can include sexual abuse of a child or young person, sexual assault of women and men and a recognition of women and men who have been sexually abused as children.

The language of abuse, neglect and exploitation has been used in the past to minimise and ignore sexual violence against people with disability, particularly people who experience violence in service systems. For this reason, it is important to have clear understandings about the terms.

- **Violence and abuse**: includes assault, sexual assault, constraints, restrictive practices (physical and chemical), forced treatments and interventions (including reproductive), humiliation and harassment, financial and economic abuse and significant violations of the privacy and dignity of people with disability on a systemic or individual basis.
- **Neglect**: includes physical or emotional neglect, passive neglect or wilful deprivation. A single significant incident or systemic; depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.
- **Exploitation**: is when a person takes advantage of someone else. This could include improper use of another person or withholding assets, labour, employment or resources including taking physical, sexual, financial or economic advantage of another person.\(^6^5\)

The prevalence and risk of violence, abuse, neglect and exploitation of people with disability which led to the Disability Royal Commission is well documented, although for a range of reasons, precise statistics are not very reliable.\(^6^6\) The Australian Institute of Health and Welfare, using data from the Australian Bureau of Statistics *Personal Safety Survey 2016*\(^6^7\) outlines that:

- 25% of women with disability have experienced sexual violence after the age of 15, compared with 15% without disability.
- 6.6% of men with disability have experienced sexual violence after the age of 15, compared to 3.9% of men without disability.
- 40% of women with disability have experienced physical violence, compared with 26% without disability.
- 47% of men with disability have experienced physical violence, compared with 38% of men without disability.

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\(^6^4\) (Dyson, Frawley, & Robinson, 2017)
\(^6^5\) (Mikton, Maguire, & Shakespeare, 2014)
\(^6^7\) (Australian Institute of Health and Welfare 2019) The limitations of the ABS Personal Safety Survey include the exclusion from the survey of people with communication disability and of people living in institutional settings, which prevent them from being interviewed privately.
• 21% of people with disability have experienced intimate partner violence, compared with 13% without disability. 68

People with psychological disability are most likely to have experienced sexual violence after the age of fifteen (35%), followed by people with intellectual disability (23%).

Of those who experience violence, 74%, or 2.0 million adults with disability have experienced multiple incidents of violence, compared with 62% of adults without disability. These figures are undoubtedly an underrepresentation, as this survey collects data only from people who are able to independently complete questionnaires, and not from people living in residential services of any kind, where violence is known to be higher.69

A wide range of literature and data collectively indicates that people with disability are significantly more likely to experience violence, abuse or harassment at some point in their lives than those without disability.70 We also note here that identifying disability among victim-survivors of sexual abuse is complex where the impact of trauma may present or be conflated with disability (diagnostic overshadowing). The higher incidence of any form of abuse for people with disability means it is likely people with disability have experienced cumulative trauma at the time of support seeking.71

Available data demonstrates that from childhood, people with disability experience bullying, restraint, seclusion, violence, abuse, domestic and family violence in numbers higher than their non-disabled counterparts, and this is also higher for people within the priority populations groups.72 Women with Disabilities Australia note that women and children with disability experience many of the same forms of violence that all women and girls experience, and also face additional violence at the intersection of gender and disability. These forms of violence are ‘particular to their situation of social disadvantage, cultural devaluation and increased dependency on others’.73 They can include denial of provision of essential care, forced contraception or even sterilisation, forced or coerced psychiatric interventions, medical exploitation, withholding of or forced medication, forced isolation, seclusion and restraint, violations of privacy, and humiliation.74 For people with disability who live in closed settings or who have few informal support relationships, the risks of similar abuses are also high.75

Children and young people with disability are estimated to experience violence, abuse, neglect and exploitation at rates almost three times that of their non-disabled peers.76 The most reliable prevalence statistics estimate a pooled prevalence rate of 8.9% for children with disability – that is, by pooling the data across studies with widely divergent results, the estimated rate at which children with disability experience sexual violence is 9%. This represents a risk almost three times greater than to children without disability.77

A key risk factor for children, identified in research conducted for the Royal Commission into Institutional Responses to Child Sexual Abuse, is that many children and young people with disability can have very different living patterns to their peers without disability. This includes segregation, social isolation and more limited connections to peers and community supports.78

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68 (Australian Institute of Health and Welfare, 2019)
69 (Frohmader, Dowse & Didi, 2015)
70 (Australian Institute of Health and Welfare, 2019)
71 Children with disability are more likely to disclose sexual abuse earlier than those without as found in private sessions information given to the Royal Commission into Institutional Responses to Child Sexual Abuse (2017a).71 However, disclosure does not always lead to accessing support. Other sources suggest the opposite and children with higher complex disability needs are less likely to disclose.
72 (Fromhader, 2019)
73 (Frohmader et al., 2015)
74 (Frohmader et al., 2015)
75 (Robinson & Chenoweth, 2012)
76 (Llewellyn et al., 2016)
77 (Llewellyn, G, Wayland, S, Hindmarsh, G 2016)
78 (Robinson, 2016)
Children and young people who have engaged in problematic and/or harmful sexual behaviours are a ‘diverse group with complex motivations, background experiences and varying types of abuse or offending behaviour’. Problematic and harmful sexual behaviours are identified along a continuum which takes into account, age and developmentally appropriate behaviours. Consistent with the royal commission (CARC) and the literature we use the term problematic and/or harmful sexual behaviours (PHSB) throughout this report. Four fields of identification detailed in the literature focus on whether children’s behaviour is developmentally expected; socially acceptable; consensual, mutual, reciprocal; and from a place of shared decision making.

Evidence is scant on the prevalence and risk of children and young people with disability who have engaged in problematic or harmful sexualised behaviour. It is recognised that these children and young people are disproportionately likely to present to services for support. One study indicated that 38 per cent of young people referred identified as having an intellectual disability. Practitioners in interviews indicated that a high proportion of their caseloads comprise children and young people who have intellectual disability. It is also important to note that children and young people with harmful and problematic sexual behaviours are also often victims of sexual violence themselves.

The literature and practice is united in the importance of connecting prevalence with risk and context – that we do not conflate disability with problematic or harmful sexual behaviour. Children with intellectual disability are at greater risk of abuse, harm and neglect, less likely to receive sex education (and so less likely to understand the harmful nature of their behaviour), and are likely to be more ‘visible’ to professionals making them subject to a higher level of scrutiny.

2.3 Royal commissions and other inquiries

Expectation for change is building as a result of numerous inquiries and royal commissions into the treatment of people with disability conducted by the Commonwealth and states across Australia over the last decade. The Royal Commission into Institutional Responses to Child Sexual Abuse (Child Abuse Royal Commission, CARC, 2017) identified increased risk and vulnerability for children with disability due to ‘higher rates of institutional contact’, dependence on others for support, community attitudes to disability, and ‘support needs and impacts associated with different impairments’. The Commission included several case studies into disability schools and service providers, and found that 4.3 per cent of people who attended private sessions indicated they had disability at the time of the abuse. The CARC noted that attention to the needs of children and adult survivors with disability are an ‘integral part of best practice prevention and response across the whole community’.

The Child Abuse Royal Commission made 406 recommendations and the rights of children and young people with disability are embedded in those recommendations. CARC Child Safe Standards for organisations made specific recommendations for children and young people with disability, children from culturally and linguistically diverse communities and children from Aboriginal and Torres Strait Islander communities.

Recommendations made in the Final and Criminal Justice Reports of the CARC 2017, and research conducted on Commission’s behalf underpin the need for addressing the issue of service

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79 (Hackett, Phillips, Masson, & Balfe, 2013)
80 (Hackett, 2010)
81 The study was of 700 children and young people, where disability status was recorded, 38 per cent (n=241) with learning disability, 62 per cent (n= 392) with no cognitive impairment.
82 (Hackett, Branigan, & Holmes, 2019 ; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
83 (Meiksans, Bromfield, & Ey, 2017)
84 (Hackett, Branigan, & Holmes, 2019)
85 (Hackett, Phillips, et al., 2013
86 (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017d, A brief guide to the Final Report: Disability)
87 In Private sessions victim-survivors spoke confidentially about their experience of abuse to a Commissioner. Commissioner conducted over 8000 private sessions with survivors or people close to them, accounting for 6875 individual accounts.
88 (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017d, A brief guide to the Final Report: Disability)
89 (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017b)
support for people with disability who have been victims of sexual abuse and violence, and children and young people with disability who have engaged in problematic and/or harmful sexual behaviour. CARC recommendations cover areas related to victims of child sexual abuse and therapeutic interventions for children and young people with harmful sexual behaviours, including accessible support services, out-of-home care responses to children with disability, and child sexual abuse prevention education including online safety.

Some recommendations directly focus specific attention to the need for NSW Health to develop a disability access strategy to better address the needs of children and young people with disability who have experienced sexual violence and recommendations for children and young people who have engaged in problematic and/or harmful sexual behaviours.

**Recommendation 9.7**

Primary Health Networks, within their role to commission joined up local primary care services, should support sexual assault services to work collaboratively with key services such as disability-specific services, Aboriginal and Torres Strait Islander services, culturally and linguistically diverse services, youth justice, aged care and child and youth services to better meet the needs of victims and survivors.

**Recommendation 10.2**

The Australian Government and state and territory governments should ensure timely expert assessment is available for individual children with problematic and harmful sexual behaviours, so they receive appropriate responses, including therapeutic interventions, which match their particular circumstances.

**Recommendation 10.3**

The Australian Government and state and territory governments should adequately fund therapeutic interventions to meet the needs of all children with harmful sexual behaviours. These should be delivered through a network of specialist and generalist therapeutic services. Specialist services should also be adequately resourced to provide expert support to generalist services.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) is currently underway and will present its findings in 2022. This royal commission is a significant inquiry and the latest in a series of investigations into violence, abuse and neglect of people with disability. A range of other inquiries relevant to violence against people with disability have been conducted in the last five years. These include, and are not limited to:

- Commonwealth of Australia 2015: Senate Inquiry - Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age-related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability
- NSW Ombudsman 2018: Abuse and neglect of vulnerable adults in NSW – the need for action
- Victorian Government 2016: Inquiry into Abuse in Disability Services
- Australian Law Reform 2017: Elder Abuse – A national legal response
- Victorian Royal Commission into Family Violence 2015
- Special Taskforce on Domestic and Family Violence Not Now, Not Ever: Putting an End to Domestic and Family Violence in Queensland 2015

A substantial volume of recommendations for change have been generated from these inquiries, calling for changes to legislation; transformation change to systems; policy development; and

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30 (Breckenridge & Flax, 2016; Llewellyn, Wayland, & Marsh, 2016; Quadara et al., 2017; Robinson, 2016)
31 Royal Commission into Institutional Responses to Child Sexual Abuse Final Report Recommendations 2017e
32 Royal Commission into Institutional Responses to Child Sexual Abuse Final Report Recommendations 2017e
significant improvements in practice frameworks to better prevent violence and abuse and respond more effectively when it does occur. Important recurrent themes include activating the human rights of people with disability; meaningfully including people with disability in mainstream violence policy and practice responses; addressing the siloed approach to policy and service provision to better address violence prevention and response; and developing useful practice to support people with disability who experience violence and abuse.

2.4 Rights context

Australia is signatory to United Nations Convention of the Rights of Persons with Disability (2006) and Convention on the Rights of the Child (1989) and as such has legal and moral obligations to uphold the rights of citizens. These conventions outline the rights of people with disability, the rights of children, and the responsibilities and obligations of the state in relation to those rights. As signatory to both conventions Australian governments are responsible for ensuring the rights of people with disability.93

Activating the human rights of people with disability is a key challenge for governments, funded organisations and people who use them. People with disability continue to face persistent discrimination and barriers that restrict them from participating in society on an equal basis with others. They are denied their rights to be included in general education, to be employed, to live independently in the community, to vote, to move freely around their communities, to take part in cultural and sporting activities, to enjoy social protections, to access justice, to choose medical treatment and to enter freely into legal commitments such as buying and selling property. All of these daily barriers constitute an ableist experience, in which people with disability have to advocate across their daily lives.94 Acknowledging the impacts of these wide-ranging personal, systemic and institutional barriers and taking action to address them is essential for both understanding and addressing the causes of deep-rooted problems such as sexual violence.

2.5 Policy and practice context

Commonwealth frameworks, strategies and plans to reduce violence and protect children scaffold NSW policies. In the violence policy field, these include the National Plan to Reduce Violence Against Women and their Children 2010-2022, and the National Framework for Protecting Australia’s Children.95 Both plans aim to reduce violence by improving the ways federal and state governments work together, increasing support available to women and children, and increasing innovation and targeted change strategies.

National disability policy is framed by the National Disability Strategy 2010-2020. This provides a guide to shared national responses following the signing of the UNCRPD to promote inclusion of people with disability in all parts and operation of their communities, focused around six key areas of improvement. The Strategy sets up guidelines for state Disability Inclusion Action Plans. The next Strategy is currently under development.

The National Disability Insurance Scheme (NDIS) is the policy setting for funded disability supports, particularly where there are interface issues between specialist disability support and mainstream support services. The NDIS provides funding to eligible people with disability to access their choice of specialist disability or mainstream community support and services. The oversight mechanism for the NDIS is the NDIS Quality and Safeguards Commission, an independent agency which was established to monitor and improve the quality and safety of NDIS-funded supports and services.96 The lived realities that people with disability regularly negotiate the intersections of mainstream and specialist disability services have not been well accounted for in national policy.97 To date these policies have not taken account the high rates of violence experienced by women.

94 (United Nations Human Rights Office of the High Commissioner 2020)
95 (Council of Australian Governments 2008, 2009)
97 (Robinson, et al, 2020b)
and children with disability, or the consequent complex needs for safety planning and responses to support people with disability.

### 2.5.1 NSW Policy settings

#### Violence prevention policy

The NSW Government’s *Domestic and Family Violence and Prevention and Early Intervention Strategy* 2017-2021 includes priorities to prevent and intervene to protect people from domestic and family violence, including those people in the priority population groups.98

The NSW Domestic and Family Violence Blueprint for Reform 2016-2021: Safer lives for women, men and children and NSW Sexual Assault Strategy 2018-21 outlines goals and actions for developing and improving the service system to support the National Plan to Reduce Violence against Women and Their Children.99 These policy documents embrace a holistic approach to change, working from prevention, intervention and education, support for victims, perpetrator accountability, and service systems and structure. Evaluations are built into the strategies to ensure improved outcomes for victims and for offenders. Both of these policies take an intersectional approach and highlight the need for services to work with priority population groups.100

The NSW Health *Integrated Prevention and Response to Violence, Abuse and Neglect Framework* (IPARVAN) framework seeks to strengthen NSW Health services in responding to violence, abuse and neglect in NSW, and maps the need for change and a public health approach to Government reform to ensure people in NSW live free from violence.101 The IPARVAN framework adopts a public health approach to shape key goals for policy change in the area of Domestic and Family Violence, working from prevention and intervention, and a continuum of and integration of services to meet a person’s needs. The policies address violence, abuse and neglect, including domestic and family violence and children and young people who engage in problematic and/or harmful sexual behaviours. The evidence in the framework and guidance in NSW policies also notes that violence, abuse and neglect is rarely experienced as a single incident and different forms of interpersonal violence are often co-occurring or experienced across the lifetime. This is the driver for integrated services and underpins the need to better integrate responses to disability and sexual violence.

IPARVAN identifies key strategic areas to provide increased accessibility, holistic, collaborative care and service responses, care for clients and families, equitable and comprehensive responses, ‘addressing context-specific needs for vulnerable clients and families’ 102 areas for service improvement with strategic direction of integration in NSW Health services and other partner organisations.

People with disability and/or mental illness are identified as a priority group in the IPARVAN. The importance of an intersectional approach (see Section 3.8) is highlighted in the higher rates of disability in other priority groups including Aboriginal people, women in pregnancy and early motherhood, young women and girls, culturally and linguistically diverse people, migrants and refugees, and lesbian, gay, bisexual, transgender, queer and intersex people.103 The IPARVAN framework provides an overarching reform direction for sexual assault services and New Street services. This needs assessment provides evidence to inform the direction and content of the strategy for implementation.

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98 (NSW Ministry of Health, 2016)
99 (NSW Ministry of Health, 2018)
100 (NSW Ministry of Health, 2019, The Case for change, p. 23-25) ‘Priority population’ is a term used to refer to diverse groups for whom there is significant evidence of heightened vulnerability to violence, both in frequency and severity, and who may encounter a range of specific barriers to seeking support and securing safety, related to intersecting identity-based and situational factors and experiences of discrimination. While a range of terminology is used by and to describe these groups, ‘priority population’ is consistent with the NSW and national policy landscape (Council of Australian Governments, 2011; Centre for Epidemiology and Evidence, 2018)
101 (NSW Ministry of Health, 2019, p. 3)
102 (NSW Ministry of Health, 2019, p. 14)
103 (NSW Ministry of Health, 2019, The Case for change, p. 25)
Specific to this needs assessment are policy directives, Responding to Sexual Assault (adult and child) Policy and Procedures, and the New Street Service Policy and Procedure Guide. Both these policies outline specific guidelines for working with people with disability. The Responding to Sexual Assault policy acknowledges services responses need to address specific risks and barriers for people with disability who have experienced sexual violence. The policy outlines the need for increased collaboration across service sectors (disability, sexual assault, police, justice), decision making and crisis management. The New Street policy notes a significant number of participants in their program present with Autism Spectrum Disorder and/or cognitive impairment, and others where family members, parent and carers also with disability. New Street policies require them to comply with the NSW Disability Inclusion Action Plan and respond to the needs of the person seeking support, including using appropriate resources, and training to work with young people with disability.

The NSW Disability Inclusion Act 2014 has two primary functions. It commits the NSW Government to improving the accessibility of mainstream services and communities; and regulates specialist disability supports, services, and provides safeguards. The DIA draws on the UNCRDP and is rights-based legislation; and makes reference to the principles, and also identifies specific requirements for government agencies. The DIA also provides guidelines for transition to the NDIS and is currently under review. Under the Act, Disability inclusion action plans are required by all local councils, intended to improve access and accessibility at a local level for people with disability. The Act also makes provision for the Ageing and Disability Commission, a statutory independent body aiming to meet a gap in safeguarding functions by focusing on abuse in familial, informal and community contexts.

Implementation of the NSW Disability Inclusion Act has activated a range of policies specific to people with disability in multiple jurisdictions. Key domains with responsibility for responding to sexual violence against people with disability include NSW Health and Department of Communities and Justice. For example, core health policies and implementation frameworks include the NSW Agency for Clinical Innovation Building capability in NSW health services for people with intellectual disability: the Essentials, and NSW Health Disability Inclusion Action Plan.

Also, important to note is the establishment of safeguarding mechanisms for people with disability in NSW, particularly the establishment of the NSW Ageing and Disability Commissioner and NSW inclusion in the national NDIS Quality and Safeguards Commission framework.

2.5.2 Practice context

Less than 1% of new clients referred to NSW Health funded Sexual Assault Services between July 2017 and March 2018 identified as people with disability. NSW Health data suggests a higher proportion of people with disability do not engage with the services due to accessibility issues. These referral rates are significantly below the estimated prevalence rates for sexual violence among people with disability. These statistics are, however, unreliable and restricted by current data reporting constraints, and as highlighted earlier the complexity around people choosing to identify as being a person with disability. Stakeholders in consultation and policy documents indicated that children, young people and adults access services through pathways via the health and justice systems, emergency departments and police responses to violence, disability service provider, mental health service referrals and support service outreach lines such as 1800RESPECT. Children and young people who have engaged in problematic and/or harmful sexual behaviours may be referred through education services.

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104 (NSW Government, PD2020_006)
105 (NSW Government, PD2018_035)
106 (NSW Government, PD2020_006, p 67-70)
107 (NSW Government, PD2018_035, p76)
108 (Robinson et al, 2020b)
109 (Robinson et al, 2020b)
ECAV is a state-wide unit responsible for workforce development in the specialist area of prevention and response to violence, abuse and neglect, including Aboriginal family violence, child abuse and neglect, sexual assault, medical and forensic issues, intimate partner violence, abuse of older people and male domestic and family violence interventions. ECAV also offers community development programs to strengthen capacity to address family violence in Aboriginal and migrant and refugee communities. ECAV provides state-wide face to face and virtual training, agency and policy consultation, clinical supervision and consultation, and resource development for NSW Health, other government and non-government organisations.\textsuperscript{110}

The central focus of ECAV workforce development activities is to improve the emotional, social and physical wellbeing, protection and safety for victim survivors of violence, abuse, neglect and exploitation. Trauma-informed, culturally inclusive and gender sensitive approaches as well as rights-based responses underpin ECAV training, aiming to build capacity around person centred, integrated and collaborative practice. ECAV has embedded co-design principles into the governance of, and development and delivery of training programs for Aboriginal, Migrant and Refugee communities. Community-based participatory research methodology is applied to develop practice-based evidence through close collaboration with people with lived experience and relevant practitioners. ECAV is committed to further embedding co-design principles and practice into the governance of and development and delivery of training and resources for people with disability.

\textsuperscript{110} NSW Health, Education Centre Against Violence, Who we are http://www.ecav.health.nsw.gov.au/who-we-are/ August 17, 2020
Part II: Evidence for improving accessibility

3. Practice principles for accessible services

Clear evidence of practice principles to guide service provision emerged from the literature and the interviews. In this part of the report, eight short sections outline practice principles underlying service approaches that underpin positive practices. These apply to both sexual assault services and services for children and young people who have engaged in problematic and/or harmful sexual behaviours.

**Practice Principles for accessible services**

1. Activating a human rights-based approach
2. Improving access and accessibility
3. Recognising and responding to barriers
4. Countering discriminatory attitudes
5. Recognising and responding to capabilities
6. Taking a holistic approach
7. Using a trauma-informed approach
8. Applying an intersectional lens

3.1 Activating a human rights-based approach

Rights-based approaches ensure all people, including people with disability, are equal citizens in society and have access to the full range of civil, political, economic, social and cultural rights. Rights-based approaches include participation, where people with disability have the right to participate in all decisions affecting them; accountability, where services are accountable, monitored and compliant with human rights; and non-discrimination, where people who are marginalised and vulnerable are supported to access their rights as citizens.

Understanding human rights and the obligations attached to them are key to ensuring people with disability have access to the services and supports they want and need. Human rights-based principles and service practices that arise from those principles ensure people with disability are afforded dignity and respect, and their self-determination and beliefs are empowered. Structural inequalities and denial of rights in social and economic areas lead to increased vulnerability to violence for women with disability. A rights-based response ensures societal resources and supports are employed to afford equal opportunities for participation and social inclusion for people in marginalised populations.

Acknowledging human rights approaches should be a key underpinning of violence services. To activate this, the literature notes services need increased awareness and understanding of violence against women and children with disability, and increased skills. Skills focus on knowledge and training for staff in understanding of human rights and obligations, violence against women with disability, and communication with people with disability.

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111 Women With Disability Australia have a range of resources and training that operates from a human rights based approach to support women and girls with disability. [http://wwda.org.au/about/](http://wwda.org.au/about/) accessed June 18, 2020
113 (Jessiman & Carpenter, 2018)
114 (Didi, Soldatic, Frohmader, & Dowse, 2016)
115 (Mandl, Schachner, Sprenger, & Planitzer, 2014; Healey, 2014)
116 (Healey, 2014; Women with Disabilities Australia (WWDA), 2016)
The knowledge of people with disability forms the foundation of this approach recognising that ‘they are the experts in their own lives and can contribute a unique perspective on appropriate services and support needs’. A consumer representative stated in the interviews that information should be adapted to ensure they can participate and make decisions about their own lives, and not through support workers or family members. A policy maker emphasised the universal and intersecting importance of human rights in making change that improves people’s lives:

*fundamental rights make a significant difference to access and support*

(Disability and sexual assault services policy maker)

### 3.2 Improving access and accessibility

Sited within a human rights approach are the key issues of access to, and accessibility of, services. In short, access can be thought of as ‘I have access to’, and accessibility as ‘it is usable to me’. Access refers to the availability of appropriate services with capacity (without a waitlist) that are located within a reasonable geographic distance. This includes timely access to assessments and services, and service reviews. Considerations around improving access has implications for improving the physical location and availability of services to people with disability – in terms of physical and sensory accessibility, and also in terms of geography.

Accessibility describes the nature of services – the way services are designed; how they are adapted and adjusted in a flexible way, and acknowledge and respond to diversity in disability populations. From the perspective of women with disability themselves, priorities around accessibility have been identified through research as being approachability (how comfortable they felt approaching the providers), acceptability (how close a cultural fit the service was to their values) and appropriateness (how well the service location and operation fit their preferences).

The principles of access and accessibility were endorsed and extended across the interviews. It was highlighted by stakeholders that service accessibility is often determined by the capability of the person providing disability support, including knowledge and willingness to facilitate support services:

*Disability support staff are the gateway to really whether someone gets linked in with appropriate services or not. And even if you've got fully accessible sexual assault services it's still those disability support staff, that in many cases are going to be a key determinant in whether the person is linked in with those services or not.*

(Disability and sexual assault policy maker)

Participants applied the concept of accessibility in the broadest sense of the term, where services draw from a range resources and effective tools (such as supported decision-making) to ensure their support creates a physically, culturally and emotionally safe space. This was exemplified in the view access and accessibility in a rights-based framework understands the person seeking support is a

*person first [and services] work with that individual and acknowledge their base, their language, their country, their disability supports and accessibility.*

(Consumer representative)

### 3.3 Recognising and responding to barriers

Women with disability encounter issues of safety and security, being believed and listened to, and having their legal and human rights respected in their daily lives. Challenges in accessing services includes recognition of, and responding to these barriers. Studies have systematically

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117 (Dyson et al., 2017)
118 (Robinson et al, 2020a)
119 (Robinson et al, 2020b)
120 (Barrett & Pierre, 2011; Mandl et al., 2014)
121 (Robinson et al, 2020b)
122 (Maher et al 2018)
123 (Maher et al 2018)
noted barriers to services also include recognition of violence in the lives of people with disability, community and service providers’ attitudes toward people with disability, and the impacts of siloed service delivery.  

Barriers to accessing services identified within the stakeholder interviews include recognition, perception and understanding of sexual violence and in particular violence against people with disability; services being able to work with priority population groups and their specific needs, service provider capacity in terms of skills and availability, siloed and non-collaborative service provision, that is, not adopting an holistic approach, community knowledge of services, and risks following disclosure. Stakeholders expressed these concerns across the interviews.

One of the key things that we’ve seen already from our work is that violence against people with disability and our focus, is adults with disability, and older people. That the focus, violence against them and particularly sexual violence against adults with disability, it’s not recognised as a domestic and family violence issue. (Disability and sexual assault services policy maker)

A primary concern when accessing services for people with disability identified across the consumer groups and practitioners was the siloing of support and lack of integration across services.

Well it’s just, you know, prior to the NDIS at times you could have success setting up secondary consultation and warm referrals. But now, with only 10% of people with disabilities being eligible for the NDIS and it being unit costed… Also, there being a whole lot of layers around contacting the NDIS or the LAC or a service provider, setting up those links is almost impossible. (Consumer advocacy representative)

Barriers identified by stakeholders in services for children and young people with disability who engage in problematic and/or harmful sexual behaviours, similar to sexual assault service provision were concerned with identification and recognition of behaviours and community attitudes to children and young people with disability and sex and sexuality education. Stakeholders identified other gaps and barriers which included, timely availability of services, education and resources that are appropriate for children and young people regarding sex and sexuality including safety online. Workforce skills and capacity to identify and work with children and young people with disability has implications across sectors, as disability workers, out-of-home-care workers, teachers and other people involved in the child or young person’s life need skills to support them.

Appropriate diagnosis of impairment and support needs was one barrier practitioners identified and this linked to cross sector engagement. A stakeholder explained.

And I’ve been told point blank in helping young people through NDIS processes with their families, “That’s not an issue we can address. Can you reframe that into a disability-based issue?” I’m like, “Well, no, that’s not the appropriate response. That’s not where they’re at.” Actively seeking a reframe that is more diagnostic, particularly for those kids from those early trauma backgrounds with significant domestic violence experiences, or multiple complex traumas, the way that that system is set up, or the way it’s interpreted by some workers means that there is a seeking of incorrect diagnoses because it’s more convenient at times, and then that sticks as well.

(Problematic and/or harmful sexual behaviours services provider)

Stakeholders noted there is a lack of timely and appropriate support for children and young people with disability in regional, rural and remote areas. They also identified that for many service users there are family members with disability who also require adequate support to engage with support services.

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124 (Dowse et al 2013; Dyson et al, 2017; Maher et al 2018)
3.4 Countering discriminatory attitudes

The importance of actively countering discriminatory attitudes and practices through education, building capacity in violence response services, and fostering strong collaboration across sectors is evident from the findings in the research and interviews.

Long-standing discriminatory attitudes towards people with disability, and negative community attitudes toward their sex and sexuality, education and rights are frequently identified across the literature.\textsuperscript{125} These attitudes from families, workers and the broader community, commonly view people with disability as non-sexual, hyper-sexual or inappropriately sexual.\textsuperscript{126} These stereotyped and inaccurate views are pervasive, and impact on both the victim-survivor’s capacity to disclose, and the responses by others to that disclosure.\textsuperscript{127} The literature also points to particular barriers for victim-survivors with intellectual disability, who can be viewed by services to lack capacity and credibility due to their intellectual impairment.\textsuperscript{128} For young people with problematic or harmful sexual behaviours, these attitudes may prevent them from accessing sex and sexuality education, or accessing help following incidents.\textsuperscript{129}

The effects of these pervasive discriminatory views across practice domains were reflected in the interviews, where stakeholders spoke of multiple ways that negative attitudes to people with disability affects their capacity to exercise their rights. One participant (policy maker) noted that this attitude is evidenced by the recent High Court challenge by the Government against providing sex work services within NDIS funding. Several service providers noted the effect of assumptions about disability on access to services:

\begin{quote}
… violence against people with disability [is] not recognised as a domestic and family violence issue and instead the disability of the person seems to colour the [service] response. (Disability services provider)
\end{quote}

Consumer representatives in particular explored the tension of ‘protecting’ people with disability and limitations on access and rights through assumptions about ability. It is widely understood that people within the networks of people with disability (family, friends, support workers) can limit or amplify their voices.

\begin{quote}
There’s also the protective elements that could come into play from often family or parents who are trying to be supportive and loving and coming from a good place, but at the same time sometimes limiting options for people for their children. So, there’s all those elements that kind of can come up and if there isn’t a discussion around ableism and those elements of unconscious bias, I think there’s an opportunity there for people to really question their assumptions around disability. To ensure that they are questioning when they’re providing a service. (Consumer group representative)
\end{quote}

Clear feedback from both consumer groups and disability service providers focused on how attitudes toward people with disability can impact on how people are listened to, understood, and judged when engaging with health services. Assumptions by service providers, health, police, and others, about capacity and behaviours, can lead to people with disability being viewed as ‘untrustworthy’ or ‘unreliable’ witnesses. It is also present in the diagnostic overshadowing that can result in service providers interpreting the trauma and violence signals of people with disability as challenging behaviour or other features related to their impairment.\textsuperscript{130}

\textsuperscript{125} (Ballan & Freyer, 2012; Olsen & Carter, 2016; Sammet Moring, Parish, Mitra, & Alterio, 2019)
\textsuperscript{126} (Child, Oschwald, Curry, Hughes, & Powers, 2011; Fraser-Barbour, Crocker, & Walker, 2018; McGilloway, Smith, & Galvin, 2020)
\textsuperscript{127} (Hackett et al., 2019; Quadara et al., 2020)
\textsuperscript{128} (Kessler, 2014)
3.5 Recognising and responding to capability

The inherent capability and resilience of people with disability is often overlooked in service paradigms which emphasise a deficit framing, prioritise the knowledge of service providers over the lived experience of people themselves, and have little flexibility to maximise people’s strengths.

Strengths-based approaches have a strong and well-established evidence base across multiple fields, including the violence, education, social work and disability support sectors. This includes recognising that people with disability employ patterns of resistance, resilience and demonstrate other strengths to maintain their safety. In the context of sexual violence against people with disability, the evidence is less clear that strengths-based approaches are consistently applied. In the face of other evidence about the weight of negative experience and the effects of discrimination, recognising and responding to capability in people with disability is especially important. This can be applied at the level of individual practice; in building skill in the workforce; and in building the capacity of the sector(s) (refer to section four, below, for examples of practice).

3.6 Taking a holistic approach

The literature identifies a holistic approach as a key principle when working with and supporting victim-survivors of sexual violence and children and young people who engage in problematic and/or harmful sexual behaviours. A holistic approach positions the response to sexual assault within the broader context of the person’s health and wellbeing needs and engagement with systems, including housing, financial support, cultural support, medical care, mental health or drug and alcohol support, etc. There is strong evidence in research and practice that responding to people’s needs reduces risk of violence and abuse and contributes to safety and wellbeing. Our Watch defines holistic approaches in the context of violence prevention and emphasises the significance of a universal approach in challenging intersectional inequality:

A holistic and truly universal approach to prevention involves challenging not only gender inequality, but other kinds of structural inequalities, negative stereotypes and discrimination, including those based on Aboriginality, disability, class and socio-economic status, ethnicity, religion, sexual identity and refugee status.

Holistic approaches respond to the individual and recognise intersectionality and the diversity of disability experience. One stakeholder explained the need to recognise diversity among people with disability.

**Recognising that everyone with a disability has different needs and diverse capacities but just recognising that some people might be very independent in some areas and some people might - can struggle in other areas ... it is very diverse.**

(Disability and sexual assault services provider)

A holistic approach is identified as culturally safe, and able to recognise diversity and abilities. Holistic person-centred support acknowledges multiple worldviews. For example, Aboriginal and Torres Strait Islander peoples’ models for healing recognise and account for varying ability, cultural and linguistic diversity, and include and situate responses within families and communities. The victim-survivor is at the centre, and approaches include the network of people, including carers/family members, community members and peer networks around the person, and their broader community.

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131 (Bateman, 2014; Crooks, 2019, The Expert Group, 2020, Hackett et al, 2019, Quadara, 2015)
132 (Douglas & Harpur, 2016)
133 (Franklin, Bradley, & Brady, 2019)
134 (Olsen & Carter, 2016)
135 (Robinson et al, 2020b)
137 (Our Watch, 2015)
138 (Barrett & Pierre, 2011)
139 (McKendrick, Brooks, Hudson, Thorpe, & Bennett, 2017)
I’m always saying, it’s everyone’s business, [individual consumer advocacy groups] can’t change [things] for people with disability, [they can’t change] the state of the sector, whether that’s in sexual violence [or other social policy areas]. It’s all our business.

(Consumer advocacy representative)

3.7 Using trauma-informed approaches

Holistic approaches include developing an understanding of trauma-informed care. Recent research recommends the need to ‘embed trauma-informed care within a holistic wellbeing framework that integrates mental, physical and psycho-social wellbeing’.140

The disproportionately high individual experiences of violence of people with disability underlie a pervasive cultural experience of devaluing, discrimination and micro-aggression. Despite this, trauma-informed practice has not been a strong focus of research in the disability field, although it is a practice foundation in the sexual assault field. The literature on trauma-informed practice with people with intellectual disability is consistent with this practice framework, emphasising that re-traumatisation can occur without the essential principles of safety, trustworthiness, choice, collaboration, and empowerment, cultural, historical and gender issues.141 Applying trauma-informed practice reliably with people with intellectual disability in particular requires commitment to staff training, and to changing organisational culture and practice.142 The literature findings were confirmed in the interviews. The ongoing effect of the entrenched barriers were described by one stakeholder as:

people with disability have been disenfranchised and without choices for most of their lives and historically.

(Disability and sexual assault service provider)

3.8 Applying an intersectional lens

Derived from the intersecting effects of gender and race143, intersectionality theory has progressed our understanding of multiple and intersecting disadvantage in important ways. Rather than thinking in compartmentalised ways, intersectionality helps in understanding how people live ‘on multiple axes of oppression simultaneously’, including, race, gender, disability, social identity and difference.144 Because of the medicalisation of disability, people with disability have been less well served by intersectionality than other groups until quite recently.

An intersectional lens is productive to think about disability and sexual violence, where forms of discrimination and disadvantage based on people’s multiple identities can increase the severity and frequency of sexual violence and barriers to support.145 The discrimination, disadvantage and exclusion that people face due to disability also connects to other dimensions of experience, such as being young, being part of lesbian, gay, bisexual, transgender or intersex communities, being from an Aboriginal or Torres Strait Islander146 or culturally and linguistically diverse background, and/or living in a regional, rural or remote community. An intersectional lens acknowledges the history and impacts of colonisation on Aboriginal peoples, including racism and the ongoing legacy of intergenerational trauma as a consequence of enforced removal and discriminative practices in government and other services.

Conceptual understandings of disability shape institutional structures, programs and attitudes, and in turn impact on access and quality of services for people with disability. This is active in the IPARVAN framework, where an intersectional approach seeks to ‘understand the dynamics of different and often co-occurring identity-based and situational factors and structure of oppression

140 (Franklin & Smeaton, 2017; Salter et al., 2020)
141 (Gardiner, Larocci, & Moretti, 2017; Kezelman & Stavropolous, 2019; Substance Abuse and Mental Health Services Administration, 2014)
142 (Keesler, 2014; Peckham, Howlett, & Corbett, 2007)
143 (Crenshaw, 1991)
144 (Robinson et al, 2020b; Shaw, Chan, & McMahon, 2012; Stubbs, 2015)
145 (Costello & Backhouse 2019)
146 (Avery, 2018)
experienced by individuals from diverse communities, and the unique safety risks and sometimes competing needs to which these factors contribute.\textsuperscript{147}

Consumer representatives were engaged with intersectionality, and discussed issues of gender, cultural identity and disability, and the resulting barriers to services.

\begin{quote}
So just for the intersectionality of having a person with a disability, being a woman and from a CALD background that just adds more layers to wanting to speak out and open up.
\end{quote}

(Consumer representative)

\section*{4. Practices for improving accessibility in sexual assault services}

There is a high degree of consistency in the evidence about ways to promote accessibility and good practice in supporting people with disability in using sexual assault services. This section presents this evidence about practices to promote accessibility and effectiveness in services for people with disability following sexual violence. It draws from academic literature, extended by insights from expert stakeholder interviews.

Section 4.1 focuses on pathways for accessing services and practices that support referrals to sexual assault services. Section 4.2 focuses on factors that affect accessibility and quality of service provision.

The eight practice principles set out in Section 3 of this report underpin any service response.

\subsection*{4.1 Pathways, referral and access to effective sexual assault services}

Effective pathways are facilitated through accessible information, a person’s capacity an opportunity to disclosure experiences of sexual violence, and timely and appropriate referrals. Pathways to support need to be accessible, publicly well-known, easy to find and participate in, with victim-survivors confident they will be safe following disclosure.\textsuperscript{148} Successful pathways and referrals for accessing sexual assault services for people with disability depend upon a set of non-sequential events. Firstly, understanding, knowledge and attitudes of sexual violence signal that people with disability and their networks, carers/family members, community members and peer networks, that recognise or identify sexual violence. This includes education that helps shift community attitudes about sexual assault and increases awareness of the dynamics that can act as barriers to victims disclosing such as responsibility, secrecy, protection/loyalty and power/resistance.\textsuperscript{149} Secondly, people within their network need to understand disclosure, which may come about through direct or indirect means, or via emergency/crisis interventions at a time of crisis.\textsuperscript{150}

Following disclosure are referrals where the person disclosed to takes responsibility to support the person with disability to access services. Access to easy-to-explain information about the role of sexual assault services is critical for people with low literacy (see below), along with skills and knowledge around supported decision-making and working with carers or support people\textsuperscript{151}. Referrals are also dependent on people (person themselves, family, friends or person disclosed to) finding out accurate information about service options, along with the availability of accessible, knowledgeable services to receive the person.\textsuperscript{152} Referral pathways should be accessible, publicly known, easy to find and participate in, and safe (confidential, culturally, emotionally and physically safe)\textsuperscript{153}. Information should be accessible with multiple and adapted formats. Service pathways

\begin{itemize}
\item\textsuperscript{147} (NSW Government Relations, 2020)
\item\textsuperscript{148} (Dyson et al., 2017; Mandl et al., 2014; People with Disability Australia & Domestic Violence NSW, 2015)
\item\textsuperscript{149} (NSW Government PD2020_006 p221)
\item\textsuperscript{150} (Field, 2017)
\item\textsuperscript{151} (Maher et al., 2018)
\item\textsuperscript{152} (Carswell, Donovan, & Kaiwai, 2019)
\item\textsuperscript{153} (Allnock et al., 2012; Women with Disabilities Australia (WWDA), 2016)
\end{itemize}
should respond to the needs of the whole person. Referrals are prioritised around when the sexual violence took place, which may prevent timely access to support services.

4.1.1 Access to information

Research points to the value of access to accurate information about abuse and sexual violence services for improving the confidence and ability of people with disability to access sexual assault services. This information needs to be available in multiple modes of accessible language, including easy read, video and online. Advocacy and consumer groups (such as WWDA) and service providers (1800RESPECT and SECASA) have accessible resources and information and can direct people with disability to appropriate support services, see resources in Appendix.

The need for broader community information and for accessible information was strongly reinforced across the interviews with all stakeholder groups. Consumer groups heavily emphasised the need for multiple languages, easy read, digital film or video and adapted information to meet the needs of people with a diverse range of disabilities.

The NSW Council for Intellectual Disabilities has five clear practice guidelines for the improving accessibility of services, referred to as the Inclusion High5s:

1. Openness and respect for all
2. Easy to read signage and information
3. Disability awareness
4. A supportive and friendly attitude
5. Physical design and environment

While having access to information about services is an important baseline, it is in no way sufficient to overcome the entrenched barriers to access that some people with disability face due to gatekeeping of information by others, disempowerment in daily life, and lack of capacity to move freely around their community. Women with disability reported in research that building connections and trusting relationships with community workers helped them to build their knowledge and confidence to address issues of violence in their lives. Women found it very difficult to find DFV services and emphasised the need for workers across sectors to be well informed and connected to provide them with the needed information and connections.

This connects to the lack of information that people with disability have about sexual and other violence in their lives. Without a robust knowledge of what constitutes violence, it is difficult for people to feel confident to take action. A body of research demonstrates that people with disability have had diminished access to education about positive sexuality and about violence prevention, both in their childhoods and as adults. The impacts of this are significant, leaving people with reduced capacity to identify and act on harms.

The importance of support in the lives of people with disability who may not recognise or be able to act on violence in their own lives was also stressed in the interviews. This highlights the significance of practitioners working alongside identified support people in a person’s network, carers/family members, community members and peers, to bring to light and address complex issues of violence and abuse, as this comment exemplifies:

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154 (Banks, Kelly, Kyegombe, Kuper, & Devries, 2017; Fraser-Barbour, 2018; Frawley et al., 2015)
155 (Franklin et al., 2019; Franklin & Smeaton, 2017)
157 (Fraser-Barbour, 2018; Frawley et al., 2015)
158 (Robinson et al, 2020a)
159 (Curry et al., 2011; Didi et al., 2016; Dowse, Soldatic, Didi, & van Toorn, 2016)
[accessing support] relies on the goodwill of workers and support people to go in and support individuals to access that information and to … point out violence when an incident is happening. (Disability consumer group representative)

Providers of sexual assault services have an important role to play in building the confidence and capacity of people with disability, including those who are in marginalised conditions (e.g. living in closed settings), to recognise and report violence in their lives and to improve their circumstances. Some peer-led disability organisations (such as WWDA and PWDA) are working in creative and innovative ways to build connections and on rights-based projects with people in complex situations. Partnership approaches here would provide skill development opportunities for sexual assault workers, add needed expertise and active referral points for disability advocacy organisations, and contribute needed resources to people in marginalised circumstances. These projects have had success with a relationship-building approaches, which open the door through respectful relationships and similar content, rather than directly approaching people with disability on the subject of sexual assault. This has also had some value in overcoming problems with gatekeeping by staff and facility managers when seeking to access the views of people with disability.

**Improving Access: Key Priorities**

**Training delivery**

Enabling service providers to apply a human rights framework in sexual assault, health, education and justice services

Understanding disability – the diversity of people with disability who may access sexual assault services. Primary disability types, visible and invisible disability, undiagnosed and unrecognised disability, having sensitive conversations about disability. Working effectively with people with cognitive disability (intellectual disability, autism, acquired brain injury).

Building pathways to reach people with disability in multiple ways – understanding the diverse service and life pathways used by people with disability.

Making safe spaces for people with disability in communities who are less heard (Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, people in closed settings)

Working within a person’s context and cultural needs – with peer support and mentoring in Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and with LGBTI+ communities.

**Resource development**

What is sexual violence? Resources for sex and sexuality education in multiple formats for diverse audiences

**Organisational support**

Building and extending communities of practice and professional networks across disciplines
4.1.2 Disclosure

Along with knowledge about sexual violence, people with disability need opportunities for building their capacity to make disclosures about violence in their lives,\(^{160}\) through access to safe relationships, communication aids and supports\(^{161}\), and increasing opportunities to disclose and be believed.\(^{162}\) Carers and family members, community members and peers within the person’s networks need to understand disclosure may come about through direct or indirect means (such as actions or behaviour changes, health or medical observations), as well as through emergency interventions in a crisis.\(^{163}\) They may need to identify disclosures of sexual violence through behaviour or other changes, and support workers are in a key position to recognise or identify abuse or have a rapport with the person to facilitate disclosure.\(^{164}\)

*Relationships between the person with disability and their networks create opportunities for disclosure and these relationships also determine referral pathways, and often rely on a person as an ally in seeking support.*

(Sexual assault services provider).

There are risks inherent in disclosing sexual violence, and the literature outlines increased risks for people with disability. These include multiple fears, of not being believed, removal of children, loss of independence, increased violence, and not knowing what might or could be done to help.\(^{165}\) People with disability who rely on the care and support of the perpetrator are placed at increased risk if they disclose any sexual violence.\(^{166}\)

The intersectional needs of people with disability when disclosing sexual violence are also of paramount importance. These include cultural and emotional safety, particularly for women and girls in marginalised populations, Aboriginal and Torres Strait Islander peoples, migrant and refugee populations. The typical “one size fits all” approach that is so often used in mainstream service delivery has proven ineffective in Indigenous contexts, but even more when we add disability as a further layer of complexity.\(^{167}\)

Following disclosure, services need to ensure the safety of the person who has disclosed, and protect them from further harms, such as losing their children, or being at risk of more violence.\(^{168}\) Where disclosure is made, what happens next is dependent on the capacity and willingness of that person to act, in some cases increasing their vulnerability.\(^{169}\) The NSW Ombudsman’s report makes clear disclosure of sexual and other abuse is difficult for many people with disability. Service responses to reports of abuse of vulnerable adults, including people with disability living in the community, many with family, have not always protected people from further harm.\(^{170}\)

In several interviews it was mentioned that disclosures by people with disability are not always taken seriously. This view is reflective of findings of the Child Abuse Royal Commission and in the research literature.\(^{171}\) One stakeholder related their experience of working with justice agencies and the minimising and justification of violence against people with disability they had witnessed. This reference is about police response to abuse by a family member/carer.

*Police acknowledge that there’s been an assault; but will talk about the burden that the carer has to deal with on a day to day basis in providing support. Or will put it in the context of carer burden and responsibility, rather than actually seeing it for what it is, which is assault and violence against the person.*

(Disability and sexual assault services policy maker)

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\(^{160}\) (Curry et al., 2011; Iudici, Antonello, & Turchi, 2019)
\(^{161}\) (Cripps, Miller, & Saxton-Barney, 2010; Frawley et al., 2015)
\(^{162}\) (Carswell et al., 2019)
\(^{163}\) (Field, 2017)
\(^{164}\) (Fraser-Barbour, 2018; Walter-Brice, Cox, Priest, & Thompson, 2012)
\(^{165}\) (Curry et al., 2011; Fraser-Barbour et al., 2018; McGilloway et al., 2020)
\(^{166}\) (Ballan & Freyer, 2012; Curry et al., 2011; Dixon & Robb, 2016; Lund, 2011; Vaughan et al., 2016)
\(^{167}\) (Cripps et al., 2010; Vaughan et al., 2016)
\(^{168}\) (Ballan & Freyer, 2012; Sammet Moring et al., 2019; Walter-Brice et al., 2012)
\(^{169}\) (Franklin & Smeaton, 2017)
\(^{170}\) (NSW Ombudsman, 2018)
\(^{171}\) (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017a)
The impact of the complex circumstances of some people with disability on their ability to disclose violence was emphasised by practitioners working across both disability and sexual assault services in interviews. In their practice they report that in some cases, a person may need an additional network of people set up around them before any engagement with services so as to understand how to interpret their circumstances and ensure their safety, especially if the alleged perpetrator is a carer or close family member. Stakeholders described situations that require careful and strategic interventions to facilitate disclosure, for example, increasing individual supports, improving networks and disability support worker knowledge and skills.

Networks are around both risks and strengths that can be drawn on to safeguard people with disability. A stakeholder described a situation of disclosure for a young woman living in a group home.

She’d [the victim-survivor] been in group homes her whole life. She’s in her 20s. And what she presents – the staff brought her along because she was having a really sort of flashback extreme reaction to a particular male staff member and they all thought it was to do with – you know, that he was a trigger. It could be a male staff member and she remembered what had happened when she was a child.

But in the process, what happened was we unpacked the fact that he was actually you know, quietly being quite abusive and they didn’t see it because they all liked him and trusted him and so it wasn’t to do with the – it wasn’t to do with her past abuse and it was actually to do with what she was experiencing from him. And then because we’d unpacked that together, they then educated each other as a staff and confronted him and dealt with the behaviour and she felt really empowered by that. (Sexual assault services provider)

Stakeholders noted that many people with high communication needs were not afforded any privacy when communicating with health and other services due to their reliance on support people for communication support. The lack of opportunity for private and confidential conversation impacts on both disclosure and subsequent access to services. Equipping clinicians with both the communication skills and adapted questionnaires or checklists as a way to screen for domestic violence was an approach being developed for trial in Emergency Departments. This was seen as a step forward in supporting disclosures:

[People have] exactly zero safe spaces to disclose and when you’re talking about that clinician having a checklist or talking to people with disability to screen for domestic violence, I mean that kind of work is very exciting.

I’d like to see all professionals working with adults with disability to carve out, you know, just a portion of the appointment so that that person is freely able to express their views and share their wishes. Also, if there’s anything that they wish to disclose in private they have that opportunity. (Sexual assault services provider and disability policy maker)
4.1.3 Referrals

To increase referrals to support services for people who have experienced sexual violence, the research evidence identifies practical steps to improve capacity for mainstream services to be receptive to working with people with diverse disability and needs. This includes ensuring the physical and sensory access issues are addressed, and that staff are skilled around the use of communication aids and of language translators, ensuring that information is clear and adapted to accommodate a range of capacities. An example of this is in completing intake processes through narrative conversation which allows the person to tell their story in their own way, without having to answer a set of formulated questions, and only then asking the few questions on the intake form that remain unanswered by their narrative.

Timeliness of referrals and warm referrals, linking to subsequent access to other services is critical, along with personalised, flexible support with time invested in developing tailored support for the whole person. Flexibility in approach, taking a holistic approach that prioritises the person’s views and needs, and taking time was identified as key to positive referral and intake experiences for young people with learning disability accessing violence services. In one study, young people said they appreciated being asked and supported in other aspects of their lives and not only about the impacts of the sexual abuse.

Much of the research literature emphasises the disconnection between the disability and violence fields and identifies this as particularly problematic for building effective referral pathways for people with disability who use the specialist disability system. The literature points to coordinated, specialist supports and the ‘no wrong door’ approach to access services as a highly effective approach. Examples of this approach are those implemented in the UK as a means to integrate services for children and young people and in mental health policies in Australia. The ‘no wrong
“Warm referrals’ also play a role in facilitating smooth pathways to services. Discussed in research with women from immigrant and refugee backgrounds, ‘warm referrals’ support transitions between services and reduce the need for victim-survivors to repeat traumatic stories in each service encounter. ‘Warm referrals’ share information about the person’s needs, which may require additional supports from family members for people with high and complex support needs. Services can be more proactive about orientating people with disability to their environment and processes, in keeping with a trauma-informed framework. Practices to support this include building up familiarity with the environment including pre-arranged visits, quiet surrounding and social stories, and pre-emptive communication of what to expect from the service, including demonstrations and reassurance during the process. A range of collaborative relationships, including interagency connections, partnerships and co-location of services were described by stakeholders in interviews to frequently lead to warm referrals and were demonstrated to work successfully in some NSW and interstate services. These relationships were seen to support and build partnerships and collaboration across different sectors.

1800 RESPECT has implemented warm referrals through their supported pathways program, which was co-designed with women with disability. Once a woman calls the service, they are connected with an advocate or support person, who stays with them through the process, outlining what will happen and support navigation through the service.

_It’s something we do in all our referrals in terms of trauma-informed practice principles, not retelling the story, but also preparing them for the next service. So rather than just saying, we’re not the right service, we’re going to connect you with the next service. That we explain the prefix for the next service, the first person you’ll speak to is a caseworker, their role is this. So really taking time to explain and support people the best they can for that referral to be successful and to alleviate anxiety and retailing, all that kind of stuff. We did lots of work in our referrals._

(Disability and sexual assault services provider)

To facilitate both referrals made by other services, and by people themselves, information about services needs to be widely known and accessible, including online. In the interviews there was discussion about resources to support referral and accessibility of information. Consistent feedback was provided that it is important not to presume that people with disability have access to technology, supporting the case for information to be provided in multiple forms, and in multiple locations, in clinicians rooms, for disability support workers to access and pass on.

Information to support accurate and effective referrals is also needed for service providers. Interviews highlighted the inconsistent expectations that providers across different jurisdictions may have about what kind of support people with disability can expect from sexual assault services. Without clear information, referrals are less likely to be made, and people may be disadvantaged. For example, one provider related an example of a disability service provider who failed to pursue a referral for their client because they could draw on psychological support through the NDIS and the provider could not see the value of specialist support. This highlights the importance of strong collaborative connections between SAS and disability sectors, as the NDIS rules are complex and constantly changing.


177 (Vaughan et al., 2016)

178 (Frawley et al., 2015)
Positive experiences of referrals are recounted in the literature, such as police and others working with people with disability taking time to provide information and being sensitive to their needs (often referred to as person-centred), and referring on to the appropriate service.\textsuperscript{179} These service approaches accommodate the diversity of capacities and skills of people with disability. The 1800RESPECT warm referrals mentioned earlier are an example of positive referral approaches.

Several studies highlight the importance or value of advocates or support people allied to people with disability in the referral processes.\textsuperscript{180} Aligned with this, the value of specialist disability liaison positions in mainstream services (such as the police)\textsuperscript{181} has been recognised. In interviews, several stakeholders echoed the significant role that specialist disability positions in the sexual assault field have played in facilitating successful referrals into services. Previously in NSW and currently in several interstate services, the presence of a designated disability and sexual assault services worker has increased visibility of people with disability accessing sexual assault services. This has led to increased knowledge among communities and service providers of available services.

Notwithstanding these practice examples, at least one study found there is a lack of access to specialist skills, or a lack of knowledge among staff about how to engage with women whose communication challenged existing approaches.\textsuperscript{182} Feedback in the interviews supported these findings and noted the value of an ally or support worker for people with disability when embarking on accessing services.

However, the point was strongly made in interviews that information about referrals and next steps needs to be communicated directly with the person with disability and address their needs and their wishes, not those of support workers, family or others. It is important that service referrals are clear, are managed with consent, that services have the person’s wishes at the centre, and that people are treated as the ‘experts in their own lives’. As one consumer representative said:

\textit{Treat me like a person, an adult, capable, and directly, and be respectful.}

\textsuperscript{179} (Child et al., 2011; Olsen & Carter, 2016; Powell & Cauchi, 2013)
\textsuperscript{180} (Fraser-Barbour et al., 2018; Walter-Brice et al., 2012)
\textsuperscript{181} (Child et al., 2011)
\textsuperscript{182} (Frawley et al., 2015)
Improving access: Key priorities

Training delivery

Supported decision making and consent – skills and strategies for supporting decision making for people with disability, with and without communication aids, including children and young people. This activates human rights and draws on the expertise of people with disability.

Warm referrals and supporting people with disability to move from referral into active support.

Resource development

Guides about using sexual assault services in a range of alternative formats (easy read, video, community languages).

Organisational support

Enacting ‘warm referrals’, sharing knowledge about services and systems for service users.

Developing service integration through making and maintaining cross-agency relationships. What does a collaborative service system look like for people with disability? What needs to happen to avoid silo approaches?

Support within the sector – professional opportunities, networking and knowledge exchange. Problem solving together, workshops for disability and sexual assault services that focus on shared responsibility and models of support.
4.2 Effective sexual assault services and support for people with disability

Evidence from the literature outlines a range of effective practices in services for people with disability following sexual violence, although evaluation of programs is limited. Sexual violence frequently co-exists with other forms of abuse, domestic violence, neglect and exploitation. The impact of sexual violence across victim-survivors’ life domains highlights the need for collaborative and interagency service responses. Methods adapted to building on a person’s strengths and abilities through person-centred approaches are key to support people with disability. The literature outlined the following conditions that facilitate positive and effective practices, which were reinforced in the interviews. These approaches are underpinned by the principles noted earlier and respond to diverse needs of disability and intersectionality of the victim-survivor.

Effective services and support for people with disability following sexual violence

1. Are accessible: in attitudes, information and practices, and open to diversity in disability. This includes flexibility, time, communication supports and care-coordination.
2. Are relationship-based: the victim-survivor’s needs are at the centre (person-centred, strengths-based) of service responses and include family support. Service responses that are confidential, and culturally, emotionally and physically safe, using supported decision-making.
3. Draw on expert knowledge from people with disability, especially women and girls.
4. Use multisector collaboration and information sharing to accommodate the person’s needs
5. Are flexible – in approach, time, service location and outreach (and capacity)
6. Build their workforce: staff have appropriate training, capacity (availability) and competency (and confidence) and are diverse and skilled.

4.2.1 Accessibility: attitudes, information, and practices

Accessibility in the broadest sense of the term, includes attitudes, physical and ‘programmatic access’ which accommodates any impairment or disability support needs. Recent research on accessibility for women with disability draws on a framework which explains that to be accessible, services must be, approachable, acceptable, available, affordable, and appropriate. Interviews supported the findings from the literature and articulate what these mean in practice.

The literature describes a wide range of barriers for people with disability when accessing services. Negative discriminatory attitudes and stigma around disability undermine views of the capacity and credibility of people with disability when talking about things that matter to them.
including their experiences of sexual violence. Broad community attitudes also impact on access to services, where victims with disability are ‘often judged as being in some way responsible’. For children and young people, although much is made of joined up and collaborative approaches, many services remain fragmented, making access difficult. Services’ capacity to be fully accessible, with resources, awareness and education, for example to have understanding and adapted practices for people with disability, also present barriers.

Stakeholders across the interviews presented examples which illustrate the ways that attitudes and perceptions of a person’s ability have direct impact on their rights, access to support, and shape service delivery. Views from many interviews noted the need for attention to staff attitudes, supported decision making and consideration of dignity of risk. It is important for staff and services to interrogate their perspectives about victim-survivors’ skills and abilities and ‘unconscious bias’, described evocatively by a consumer group representative:

_There’s a burden of low expectations that people place on people with disabilities. In terms of what services are offered to people, assumptions about capacity to engage with the service or a person’s autonomy._ (Consumer group representative)

In one interview a sexual assault services provider stated that availability of services is also limited and recent ‘health-referred sexual assaults have priority. The NSW Health SAS policy stipulates that services prioritise access based on when the assault occurred and an assessment of clinical need, and recent events are prioritised, but not by referrer The stakeholder explained that people with disability ‘would need someone in the service who really actively advocates’ for them, as without assertive promotion of the person’s need, referrals can take a long time. Access to services in regional, rural and remote areas may entail wait times for specialist services, which prohibits timely responses. For many Aboriginal and Torres Strait Islander people, culturally appropriate and skilled workers may not be available.

Disability, sexual assault services providers, and consumer representatives emphasised that people with disability be respected and listened to, and that service providers can learn from their expertise and knowledge. In a very practical sense, language which presented key service components and processes in concrete terms and avoided abstract concepts made a big difference to women with cognitive disability. Services were deemed approachable and appropriate when they are person-centred and demonstrate respect and care. For people from culturally and linguistically diverse communities, approachability included being welcomed and not judged, being prompted and supported to open up in a sensitive way, being asked to consent about decisions and being interviewed about who might be part of conversations.

_194 (McGilloway et al., 2020)_
_195 (Mandl et al., 2014, p. 21)_
_196 (Jessiman & Carpenter, 2018)_
_197 (Fraser-Barbour et al., 2018)_
_198 (Lawrie & Testro, 2018)_

_So, I guess it’s about going to someone [for help] and not feeling like you’re just a number. You’re actually listened to._ (Consumer representative)

_I felt like I was understood._ (Consumer representative)

_Sometimes we tend to be a little bit polite or we respect that that person might not want to speak about a certain issue. But then well it could actually be really important to be a little bit uncomfortable, to really get to know that person and to maybe make more of a difference and be more useful to this person. So just kind of getting that balance right and being able to kind of just dig a bit deeper into kind of who that person is, is really important._ (Consumer representative)

_Being a person with a disability, being a woman and from a CALD background, that just adds more layers to wanting to speak out and open up._ (Consumer representative)
Several stakeholders in interviews remarked on the need for more high-quality resources and information in a range of formats to improve accessibility to mainstream sexual assault services. Although there are multiple appropriate resources available these are not well-known, and service providers often develop their own resources on an ‘as needs’ basis (see Appendix). These vary in quality and consistency, and availability of resources on a continuing basis has been identified in research as a problem in a sector where programs frequently operate on non-continuing funding.\textsuperscript{199}

Several providers and consumer groups have developed accessible resources (see Appendix). One disability consumer group described having some difficulty in disseminating information and attributed this to the fact that for many people with disability accessing information often relies on the goodwill of support workers.

\textit{For example, with our site have been developing lots of accessible resources in easy English and Auslan and even different languages and putting it online to reach a wider audience … A big problem for women with intellectual disability in particular is that many are in group homes or provisional [transitional] homes where they probably don’t really use the internet at all.} (Disability consumer group representative)

A self-assessment tool is available to support reflective practice in NSW Health Services about how to build capability to support people with intellectual disability. Much of this content is useful for building practice capacity in sexual assault services.\textsuperscript{200}

Adequate funding is needed to ensure accessibility, access and availability of services together with appropriate programs, staff skills and training, collaboration and communication across. Limited budgets have restricted implementation and prioritising of physical access in some services and the literature notes funding is needed across the family violence sector.\textsuperscript{201} Employing people with disability in planning and programs,\textsuperscript{202} using mentoring programs and peer support,\textsuperscript{203} and relationships with local communities is one way to make services more approachable. Funding these approaches to services builds on and improves cultural safety and accessibility. The importance of time to implement almost of all of the strategies across referral, intake and support processes should be underlined – in almost all cases, more time is needed to provide people with the practical strategies and trauma-informed support required.

\textsuperscript{199} (Robinson et al, 2020b)
\textsuperscript{201} (Howe & Hargrave, 2016) (Frawley et al., 2015)
\textsuperscript{202} (Frawley et al., 2015)
\textsuperscript{203} (Mandl et al., 2014)
4.2.2 Relationship-based and person-centred

There is consistent evidence in the literature on the practices that support good practice for people with disability in sexual assault services and programs. Practice which is flexible, relationship-based, person-centred and confidential, respectful of the person as expert in their own lives, using appropriate and adapted communication methods has been demonstrated to be both effective and well received by people with disability. Victim-survivors need to be able to ‘go at their own pace’, have access to a choice of ways to engage with services and have access to informal and formal support, adapted to meet the capacity, skills and strengths of the victim-survivor. This can be achieved through personalised support plans and service coordination.

Based on working with adults with intellectual disabilities, Keller’s work on planning is instructive and outlines five components for person-centred planning. First, the person is at the centre, and is engaged and involved. Second, plans include family, friends and others for perspective and support. Third, there is a focus on the person’s capabilities and the supports they need to succeed. Fourth, planning reflects the person’s life, ‘not just services’. Finally, there are processes of

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205 Single session therapy sessions working with people with Acquired Brain Injury or Intellectual Disability are structured as discrete sessions which may be part of longer-term therapy and adapted for cognitive capacity.
206 (Carswell et al., 2019; Barrett & Pierre, 2011; Budu-Ainooson, Nakua, Donkor, Mock, & Kernic, 2019; Frawley et al., 2015)
210 (Robinson et al, 2020b)
ongoing listening to facilitate change in the plan as and when needed.\textsuperscript{211} Ballan suggests a safety plan is an ‘ongoing piece of work’ and needs to be regularly revised and revisited.\textsuperscript{212}

Several studies note that people with disability often look to family and friends for support, and one study states that people with disability are more likely to turn to informal and not formal sources of support.\textsuperscript{213} Stakeholders discussed a successful peer support program for women with intellectual disability who have experienced violence provided by WWILD in Queensland (see Appendix). The support group is facilitated by a clinician, well-attended and with a waitlist. The group provided social opportunities and peer support for women with intellectual disability reducing social isolation.

The need for people to draw on relationship-based, person-centred approaches and skills resonated across the interviews.

\begin{quote}
I think it’s about being able to give information and being able to provide the right support. … And certainly, there would be a lot of trust issues unless they really know somebody that they’re comfortable…and being able to actually first of all talk about it. And then going to a place or a service even that they don’t even know, it’s going to be really hard for them to even bring it up and be able to talk about it and get their message across…so it really needs to be something built in there…what am I trying to get across? About rapport, where getting to really know a person, to understand them and be able to make sure that they’re really getting help.
\end{quote}

(Academic and self-advocate)

The literature on the needs of children and young people with intellectual disability is consistent with broader knowledge about practices conveyed in interviews. For children and young people, relationships and time, together with flexibility and person-centred approaches are key to effective services.\textsuperscript{214} The approaches adopted in these services highlight relationship-based and person-centred interventions across the young person’s life domains, and the value of collaborative work with families, communities and multiple service sectors.\textsuperscript{215} Young people indicated the importance of interventions paced to suit them, learning to manage their emotions, recognise situations of risk, without feelings of blame, opportunities to learn with their peers and wanting support for their futures.\textsuperscript{216}

In a large UK study a relational focus was used to support service provision which had goals beyond crisis support to re-establish a sense of safety for children with intellectual disability. Effective services for children who have experienced sexual violence focused on these outcomes; positive relationships, stable living situation, the child was no longer being abused, reducing trauma, and working to ensure the child feels safe.\textsuperscript{217} The goals identified by the young people were increased self-esteem, being able to talk about the abuse and being able to imagine a positive future. To achieve these outcomes staff needed to understand power and inequality, receive adequate supervision, have time to work with the young person, be flexible in how they could be contacted, where the service was provided, and how long the sessions were, work with a range of agencies and professions in a team focus based on the young person’s needs.

In the interviews, specialist services providers emphasised the importance of person-centred services in developing relationships and broader support. One provider described supporting a person with complex disability by training and building capacity of the people in their networks, carers/family members, community members and peer networks. The provider was alerted to inadequate safe practices around the person with disability and put in place training and skills development, working with the person’s support team. The support teams’ skills were enhanced to improve the safety of the person with disability. This was only possible through sexual assault

\begin{thebibliography}{99}
\bibitem{Keller} (Keller, 2016)
\bibitem{Bateman} (Bateman & Milner, 2014, p. 114)
\bibitem{Barrett} (Barrett & Pierre, 2011)
\bibitem{Jessiman} (Jessiman & Carpenter, 2018)
\bibitem{Franklin} (Franklin & Smeaton, 2017)
\bibitem{McNeish} (Barrett & Pierre, 2011; Franklin et al., 2019)
\bibitem{McNeil} (McNeish, Kelly, & Scott, 2019)
\end{thebibliography}
services as access to this form of knowledge and skills development is not available through the NDIS.

_We can be working with them [person with disability] in counselling but if their home environment is not safe or not conducive to healing and safety, then they’re not going to progress, and heal from what has happened to them or improve their safety so we do need to work with the person’s environment._

(Disability and sexual assault services provider)

Person-centred support is of particular relevance for people who have cognitive disability, who are reliant on support from other people to make some or most of their decisions, and to activate the principle of human rights. In the context of support for sexual violence services, centring support around the person is more complex than for many other people. Violence against people with disability and resulting trauma are often misinterpreted by police and other services. The literature notes that victim-survivors with intellectual disability interacting with justice systems without support are often unfairly disadvantaged and their rights being overlooked. In the UK study, young people said that a ‘personalised approach, meeting [their] specific needs’ was important and led to reduced reluctance to participate.

Relationship-based and person-centred care were highlighted in interviews with consumer representatives. These interviews focused on positive practices as a response to help seeking. Positive experiences of support were characterised by respect for, and recognition of, the person’s ability and capabilities, listening, taking time to support people, and responding to and taking requests seriously. Cultural competency, developing rapport and learning from the person’s lived experience and expertise were also identified as critical.

_A person-centred approach in every area, every field, either in the domestic violence, either in the sexual abuse, either as a peer support group ... Every person has different needs due to their disability and if you are dealing with them, with their situation if you are just not giving the importance with them - because if they have asked you that "okay this is my expectation, this is my problem and I'm contacting this organisation to solve this" you must have to see [recognise] what this person wants in his life._

(Consumer representative)

_...come as you are. So coming to a person as they are and not feeling like you’re being judged or not feeling that there’s already assumptions made of you because you’re a wheelchair user, because you’re from a non-English speaking background, because you have a physical disability. It’s so essential to feel like you’re respected and you’re not judged in the first instance._

(Consumer representative)

In another interview a service provider noted it is important and useful to learn from, and work with the network of people around the person with disability (family, friends, support worker or advocate), drawing on their knowledge and utilising the trust inherent in existing relationships. This approach responds and recognises capabilities and existing barriers. Successful collaborations with a person’s network can help to build knowledge about the person’s needs and reinforce and support any therapeutic practices.

_They [disability support workers] can be really strong allies, I think, for the person with disability who needs the assistance. But as well, really critically, also for the sexual assault service, who can really benefit from the information that some of those support workers hold about the best way to communicate with the person with disability. The best way to make them feel more comfortable in order to get the most out of the contact._

(Disability and sexual assault services policy maker)

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218 (Douglas & Harpur, 2016)
219 (Franklin et al., 2019, p. 5)
There is widespread understanding that an ally or advocate for a person with disability can support them in positive ways. However, these relationships may also hinder access to services or rights to decision making, especially in cases where the advocate is also a perpetrator,\(^\text{220}\) which highlights the need for support and interventions to employ supported decision-making and make independent advocacy available.

Supported decision-making is an important concept for people with cognitive disabilities, and one with which SAS workers may not be familiar. It refers to the process of assisting the person to make valid decisions. It is based on the premise that everyone has the right to make their own decisions and to receive whatever support they require to do so. For SAS workers, supported decision-making can be particularly relevant to the process of obtaining consent for medical and forensic examination and negotiating confidentiality and privacy with family and carers. The NSW Trustee and Guardian has extensive online resources on supported decision making, including links to a capacity toolkit to help workers in establishing when and how to enlist support for decision-making when people may lack capacity to make independent decisions.\(^\text{221}\)

Supported decision-making was emphasised widely in interviews as positive and accepted practice. Supported decision-making is ‘the provision of decision-making support which enables people with cognitive disability to exercise their legal decision-making rights’ (their legal capacity).\(^\text{222}\) The literature notes the supported decision-making model for people with intellectual disability helps them to access justice and ‘to escape domestic violence’.\(^\text{223}\) In a submission to the Senate inquiry in 2015, the Australian Cross Disability Alliance called for supported decision-making to be enshrined as a legitimate and recognised category within ‘decision making mechanisms’ and for a ‘nationally consistent decision making framework’ to be established.\(^\text{224}\) Stakeholders noted that while there is increasing knowledge about supported decision-making in the disability sector, there is still a low skills base in this and other sectors. Stakeholders noted that people working in disability or sexual assault services may have some skills, though lacked confidence in the application of these in frontline practice. Participants in one interview suggested that limited use of supported decision making could be associated with the need for attitudinal change and workforce capability building:

\[\ldots \text{there’s still a lot of workers out there who have been used to making decisions on behalf of the person and … not really giving them a voice and listening to what they want and giving them opportunities to make choices.}\]

(Disability and sexual assault services provider)

\(^{220}\) (Iudici et al., 2019; Oschwald, Curry, Hughes, Arthur, & Powers, 2011)
\(^{221}\) NSW Communities and Justice 2020
\(^{223}\) (Douglas & Harpur, 2016)
\(^{224}\) (Frohmader & Sands, 2015)
4.2.3 Expert knowledge from people with disability informing services

A rights-based approach to services ensures the views of people with disability about their support needs are the foundation of service provision.\textsuperscript{225} Staff using a human rights approach demonstrate respect for the person as an ‘expert in their own lives’. Staff, carers and family members, community members and peer networks facilitate this approach through skills in appropriate communication methods,\textsuperscript{226} spending time and developing relationships with people with disability and employing supported decision-making. In a consumer group interview, one participant strongly articulated the importance of developing capacity to speak up, and being listened to:

\textit{It takes time to build it up [being able to say what you want] and also to realise that we know what we want and because we are the experts in our own minds. They think they’re the experts but they’re not the experts. We are.}  

(Consumer group representative)

The expertise of people with disability in how violence services can provide inclusive and appropriate programs is not featured strongly in research, but is growing.\textsuperscript{227} An Australian study with women with disability using tertiary violence services found that women valued positive and trusting relationships with workers and the opportunities this opened up for them, the practical support provided, and opportunities for contact with other women who had shared similar experiences.\textsuperscript{228} One UK study with children and young people with learning disability detailed similar priorities including accessible information, having time, going at their own pace and providing opportunities to reduce anxiety and relax, by for example using fidget devices.\textsuperscript{229}

These findings were consistent with the emphasis from consumer representatives about the importance to them of honesty, fidelity and commitment to the service relationship in worker practice so that workers fulfil promises they make. It was also important to consumers that if

\begin{itemize}
\item \textsuperscript{225} (Franklin et al., 2019; Frawley et al., 2015; Walter-Brice et al., 2012)
\item \textsuperscript{226} (Jessiman & Carpenter, 2018)
\item \textsuperscript{227} (Franklin et al., 2019)
\item \textsuperscript{228} (Frawley et al., 2015)
\item \textsuperscript{229} (Franklin et al., 2019)
\end{itemize}
workers cannot do something or don’t know something, then they are upfront and follow up with the person.

In interviews, tensions between perspectives of support people and listening to the wishes of the person with disability were raised. Examples from service providers and policy makers highlighted the ways that stakeholders felt services frequently overlook a person’s capacity to make decisions about their own lives. Interviews with consumer groups overwhelmingly supported the need for services to be built on expert knowledge from lived experience and to put their needs and wishes first.

For people with disability sometimes they come with a family member and so kind of understanding that well first and foremost it’s about the person with disability. It’s talking with the person with disability as opposed to the family member or the friend but understanding those dynamics and that there’s a reason why that family member is with this person. But then it’s also kind of focusing on the person with disability and always going back to him or her. (Consumer representative)

Consumer group representatives were clear about the factors helps them to access services, many of which have workforce development implications and are underpinned by the practice principles. These are: inclusive service approaches, cultural safety, peer support and mentoring for people with disability, and building capacity in people with disability to support other victim-survivors. One consumer representative noted the need for basic disability awareness and that workers just needed to use their ‘common sense’, and gave examples: don’t stand over a person in a wheelchair; stand in front of a person with a hearing impairment so they can see your lips; use an interpreter; and always ask the person with the disability for their opinions, consent or knowledge, and not their support worker, family member or others standing nearby. Working with people with vision impairment or using mobility support, common sense is ensuring areas for meetings are uncluttered and easy to physically negotiate.

Stakeholders from policy-related backgrounds also recognised the value of peer support across services, especially for Aboriginal and Torres Strait Islander people with disability, who face additional layers of exclusion and disadvantage.

We have such a barrier with Aboriginal people accessing services and wanting to see people that do have that expertise, what we’ve been seeing that has been successful is we have Aboriginal people in peer or mentor positions and they build up a trusting relationship with the Aboriginal person.

And then once that trust is gained, and the person trusts that Aboriginal person, then that peer person or mentor, becomes like a middle person and they’re building up that relationship between Aboriginal person and the clinical specialist.

We’re really trying to encourage the establishment of more peer support workers across the work, for all sorts of population groups. (Policy maker)

Another stakeholder recognised the value of this approach for broader application:

Obviously, for Aboriginal people that works particularly well, but across the board, you know, having a partnership between a clinician and a peer worker, it just adds so much to being able to work more effectively with people. (Policy maker)
4.2.4 Multisector collaboration and information sharing

There is an evidence base to support cross sector collaboration as an effective approach for both supporting individual people with disability and for building practice expertise across the disability and sexual assault fields. Collaboration is generally premised on effective communication and information sharing, and often bound up with case management and allied concepts of support coordination.

Case management is an allied-health and social work approach to supporting a person through their engagement with a service system, with core tasks of planning, coordinating, monitoring and evaluating the options a person needs to achieve outcomes. Support coordination is commonly used to describe similar functions provided to people with disability under the National Disability Insurance Scheme (NDIS), but with a stronger emphasis on linking people to funded supports using their NDIS packages and building capacity.

For people with disability experiencing sexual violence, these focused supports have been shown to support person-centred interventions. This is particularly effective when partnered with careful alliance with the person’s advocate or support persons (for those who have decision-making impairments). Alongside this sits access to relevant and useful resources to ensure that people and their families have information in ways that they are able to absorb at the time, and later when they are at home. For families with complex trauma, for example, one recent study demonstrated that effective practices in family violence services for families with co-occurring support needs centred on intensive case management together with integrated and coordinated services. There are currently resistant gaps in accessing the level of support required for people with cognitive disability in particular who require ongoing planning, coordination, monitoring and evaluation support through a case management-type role. Both the NDIS and Health systems have reduced funding for these roles, and the Support Coordination and Family Referral Service type roles do not provide a replacement level of support for people with complex needs. This is an area for systemic advocacy and review.

In interviews, several stakeholders expressed the view that collaborative approaches between disability support workers and sexual assault service providers can support therapeutic

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230 (Dixon & Robb, 2016; Iudici et al., 2019; Mikton et al., 2014)
231 (Marfleet et al., 2013)
232 (National Disability Insurance Agency, 2020)
233 (McGilloway et al., 2020)
234 (Fraser-Barbour et al., 2018)
235 (Robinson et al, 2020b)
interventions and extend their efficacy. In one interview, a service provider explained that case
management, with client consent, includes collaboration with the range of other services engaged
with the person, and in particular effective working with the disability support coordinator:

*There might be a whole range of stakeholders that are involved in the person’s life as well,
like a guardian or just solicitors and public trustee. A whole lot of people.*

(Disability and sexual assault provider)

The literature and interviews identify case management or case conferencing as a key productive
way to support collaboration across services. Collaborative and person-centred responses can
support people with disability following disclosure and reduce risk of continued or further sexual
violence. In one interview a provider explained that women with disability receive better support
when they have a good support worker, advocate or case manager.

*There was one client where it looked like it was going to be successful but then it came
down to, and this was the main case worker that worked with this client. But what it came
down to was when that worker was on shift and was available for the client and they built
up that rapport. But then if she happened to be off shift or if she was caught up with
something else, then the ability for that to be worked through with the client lessened. She
educated the other workers as much as she could … It was the relationship that the client
was able to form with these workers that would then impact on how they were able to work
with her through these things.*

(Sexual assault services provider)

Leadership approaches, in management and clinical practice, in building skill, knowledge and
resources are evident in several parts of the sexual assault sector. These clusters of practice
expertise and resource development are important examples, not only for building quality of
practice across their organisations, but also for the role they play in shaping the wider communities
of practice they influence. For example, 1800 RESPECT has invested in co-designed processes
and resources to improve the accessibility of the 1800 RESPECT phone line, training for workers,
and an app.

**Specialist co-design to build safety for women with disability**

Sunny is 1800RESPECT’s app for women with disability who have experienced violence and abuse.

It has been co-designed with women with disability to make sure it provides the
best support for the people who use it.

The Sunny App has received Scope Communication Access certification.

Sunny uses interactive stories to talk about violence and provides a range of
options for women to find out information and take action about violence.

The Making Rights Reality (MRR) project operating in Victoria is an example of connecting sexual
assault services with justice and legal services to support victim-survivors of sexual violence.
Located in the South Eastern Centre Against Sexual Assault (SECASA), the service includes
counselling, health and advocacy (Independent Third Person) support. In the MRR trial, community
legal services and sexual assault services were co-located, with communication and advocacy
support provided through the sexual assault service. The capacity of staff was noted as a

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236 (Cripps et al., 2010)
237 (Robinson et al, 2020b)
238 (Frawley, 2013)
strength in the initial evaluation of the project and knowledge of the service had increased the number of people identifying with cognitive impairment using SECASA services.\textsuperscript{239}

Co-location supports building local relationship across sectors, which can support more efficient and person-centred practices.\textsuperscript{240}

\textbf{Co-location to build collaboration}

Working alongside people With Intellectual and Learning Disabilities (WWILD) is a co-located service comprising two programs, Sexual Violence Prevention Service and Victims of Crime – Disability Training Program in Brisbane, Queensland. WWILD is widely known across medical, mental health, and police sectors and referrals are made by these sectors or less frequently through self-referral.\textsuperscript{241}

Co-location facilitates collaboration and information sharing with the person’s consent. Alongside this, being situated together is reported by stakeholders to support interagency communication:

\begin{quote}
[Therefore] being able to collaborate as a team to help that person, the individual that we’re working with, is really beneficial. Being able to pool our collective knowledge and reflect on cases [...] as a team from different perspectives; and different pieces of knowledge that we know about that person’s life and get ideas on where to from there, is really beneficial. [For example] we might be seeing things that are happening in their lives that could really benefit [from] some more in-depth work.
\end{quote}

(Disability and sexual assault services provider)

\textbf{Improving access: Key priorities}

\textbf{Training delivery}

Peer led training of frontline workers and services about the priorities of people with disability for crisis support to enhance communities of practice and professional or service provider networks.

\textbf{Organisational support}

Case management, support coordination and collaboration

Support within the sector – professional opportunities, networking and knowledge exchange. Problem solving together, workshops for disability and sexual assault services that focus on shared responsibility and models of support.

How to structure and use ‘wraparound services’ and implement integration, build potential for co-location

Collaboration – developing service integration through making and maintaining cross-agency relationships. What does a collaborative service system look like for people with disability? What needs to happen to avoid silo approaches?

\textsuperscript{239} (Frawley, 2013)

\textsuperscript{240} (Robinson et al, 2020b)

\textsuperscript{241} Working alongside people with intellectual and learning disabilities https://wwild.org.au/who-are-wwild/, accessed June 16, 2020
4.2.5 Flexibility in services

The literature outlines a need for flexible service delivery, outreach options and alternative supports for victim-survivors. People with disability lead diverse lives. The intersectionality and diversity of people with disability can be accommodated by accessible and flexible approaches in support. Flexibility approaches, including additional time, multiple and varied supports to address the impact of sexual violence across the person’s life domains, particularly for children and young people. Flexible service approaches reflect the practice principles of activating human rights, improving access and accessibility, and recognising and responding to barriers.

In several interviews, stakeholders pointed to limitations where flexibility in service provision met broader issues around the lack of options for safe housing and effective support for people with disability. This mitigates the effectiveness of flexibility as a strategy to increase people’s safety. These limitations include a lack of choice of services, accommodation options and service responses to disclosure that fail to protect people with disability. These issues can increase risk or fail to protect people with disability from further violence. For example, when an incident occurs in a group home in a region with smaller populations with limited, or in some cases, no other housing options, the victim-survivor remains in the location of risk, and safety networks need to be put in place. Risk can also increase when there are service failures in responses to disclosure. Despite the ‘choice’ rhetoric of policy, in situations where options for referral to alternative housing or safer options for people with disability are limited or non-existent, advocates’ and supporters’ attempts to collaborate with services in the interests of the person are structurally curtailed.

The fact that people don’t often get a choice about who they live with and they might be experiencing violence from a person that they’re living with or control and they don’t necessarily have a way out. And that’s not really recognised in some of the protections that are available.

(Sexual assault services provider)

Sometimes when people are trying to report violence from a co-tenant that they – police might see it as more of a disability support issue and disability support will say if the police aren’t interested in doing anything, then we’re just going to do what we think is appropriate which might not be what the person who is being victimised agrees with and feels is safe or appropriate.

(Disability and sexual assault services provider)

4.2.6 Workforce knowledge, skills, confidence

Effective services are premised on and generally rely on staff attitudes, knowledge, capacity and skills, program approach, and funded services that support collaboration and provide appropriate support. The literature and interviewees argue that effective development and delivery of services to people with disability is grounded in the knowledge and expertise of people with disability themselves.

Staff skills in recognising support needs is an important factor in setting up safety and support plans. Young people in a UK study reported that practitioners need to be non-judgemental, and someone they can ‘share with, open up to and be listened to’, someone who provides ‘structure and consistency’. Service providers and consumer groups also identified the value of consistent and trusted relationships, and ‘creating safe relationships’.

The literature points to the need for greater cross-disciplinary knowledge - of family and domestic violence in the disability sector, and of disability in the sexual assault services sector. This point was reinforced in the interviews, with stakeholders emphasising the importance for workforce skill

242 (Robinson et al., 2020b)
243 (Franklin et al., 2019; Jessiman & Carpenter, 2018)
244 (Dowse et al., 2016)
245 (Franklin et al., 2019)
246 (Howe & Hargrave, 2016)
247 (Child et al., 2011; McGilloway et al., 2020)
development in building a community of skilled practitioners who can respond to the needs of people with disability from different vantage points, and who understand how systems work.

Implementing safety and support planning with people who need support for decision-making is a key skill for workers, and one which may be unfamiliar. Disability-informed risk enablement approaches may be particularly useful in helping people with disability to make informed and safe decisions in the context of sexual violence. A person-centred approach to risk enablement for people with disability describes the ‘four essentials’ of risk enablement as putting positives first, being proactive, staying true to preferences, and minimising harm.

Stakeholders with expertise in disability practice and policy noted that workers in mainstream and sexual assault services would benefit from more skills and knowledge about supported decision-making practice. They explained that confidence in using supported decision making could be improved by increasing worker familiarity with the impact of cognitive and intellectual disability on decision-making, and workers learning how to recognise and understand communication and cognitive issues. With these skills workers across different services can help people to participate in decisions that impact on their lives. One stakeholder identified the benefit of training for workers:

…that helped them to be on the front foot a little bit more for those kinds of situations where they’re aware that people are not going to remember what’s in a safety plan. It’s still coming from a strengths-based and rights focused framework that recognises that people have the right to make decisions. But at the same time recognises that there are some limits about people’s memory and their capacity to make a fully informed decision.

(Disability and sexual assault services provider)

The literature is divided about the benefits of assessment and screening to identify people with disability. Some literature supports improved disability assessment and screening as important to support staff to effectively respond to the needs of the person, particularly in the case of people with intellectual disability. Other research emphasises the importance of services setting up accessible and flexible processes to make their service ‘disability ready’ or ‘disability-informed’, which anticipates that people with disability will present for support rather than assuming that practice should be adapted if and when a person with disability presents. This approach recognises that much functional impairment and disability in people in crisis is undiagnosed and unrecognised by them and by others. In interviews, service providers pointed to person-centred approaches, staff capacity, flexibility, and access to resources as productive measures to respond to diversity among victim-survivors. One disability and sexual assault services provider described counsellors adapting their practices using appropriate resources rather than relying on people disclosing disability or assessments of capacity. Another explained how person-centred approaches accommodate the diverse skills and capacity of people with disability, which ‘puts the person’s choice at the centre of what we do’.  

Counselling skills and approaches that are adapted for a person’s ability.

One service provider explained clear guidelines to support people with intellectual disability in emotional regulation using a Stop and Think approach, and a traffic lights system.

Disability informed/inclusive service models

Looking beyond assessment, service providers argued for workforce skills and service approaches that are relationship-based, and trauma-informed; approaches that recognise and adapt to the needs of the victim-survivor.

248 (Bigby et al., 2019)
249 (Olsen et al., 2017)
250 (McGilloway et al., 2020, p. 33; Robinson et al, 2020b)
251 http://www.stopthinkdo.com/prog_core.php approach to social skills which can be adapted for people with intellectual disability
… getting to know the person and the individual forming relationship is really important …
general trauma informed practice and creating a safe relationship but then also helping the
person feel comfortable to say when they don’t understand something …a lot of times, we
do find people are very good at masking their disability and they’ve never benefited from
really letting someone know that they have a disability. It is very stigmatised obviously.
… keeping an eye out for those signs that someone might have a disability and ask them
gentle questions to draw that out and then identify that so they can feel comfortable to
identify that and see the benefit in identifying it. Particularly you know, we’re looking at
sexual assault services and reporting and that there can be special witness provisions
when someone has a disability and other supports that can be really beneficial in that process. (Disability and sexual assault services provider)

**Communication competency** involves building confidence to use tools and
resources to support standard verbal communication. It includes:

- Using clear and plain language to explain key concepts
- Using pictorial resources
- Building a library of resources that you know work to support the disclosure
  and/or counselling process

**Improving access: Key priorities**

**Training delivery**

- Building confidence in working with people with communication impairments,
  people with significant and complex support needs
- Building cross-disciplinary pathways for referral and information sharing
- Using trauma informed approaches through a disability lens as the foundation
  for inclusive services.

**Resource development**

- Understanding systems from the vantage point of people with disability
- A toolkit of resources to support effective communication

**Organisational support**

- Building cross disciplinary communities of practice to counter silos of expertise
5. Practices for improving accessibility in services for children and young people with disability who have engaged in problematic and/or harmful sexual behaviour and their families

This section of the report is developed for use for ECAV, New Street services and other practitioners of services to children and young people with disability who have engaged in problematic or harmful sexual behaviours. It is written in the context of existing service provision frameworks in NSW Health, where services are provided to groups under 10 and 10-17 years of age.²⁵³

The academic literature on service responses to children and young people who engage in problematic or harmful sexual behaviours is limited. While some services are in place, evaluation of programs of support for children and young people with problematic and/or harmful sexual behaviours is also limited, particularly for those programs which include children and young people with disability, where the evidence is even more minimal.²⁵⁴ Because of the lack of research specific to children and young people with disability, the evidence presented below draws on findings with children more broadly which is relevant to children and young people with disability, from the disability specific literature where available, and from the interviews. New Street policy documents note a significant number of young people with disability access their services, and many have family member, parents or carers with disability. Young people must have capacity to take part in New Street services and in general they do not work with young people with moderate or severe intellectual disability.²⁵⁵

As a baseline of good practice to support access to services, the research shows that interventions require a holistic approach to address the child or young person’s harmful behaviours together with factors that increase their vulnerability to harm.²⁵⁶ Along with early intervention and proportionate response to behaviours, the evidence highlights prevention of harm as an intrinsic part of service support. Other practice principles of activating children’s human rights, improving access and accessibility, recognising and responding to barriers and capability, countering discriminatory attitudes and adopting trauma informed and intersectional lenses are relevant to these services. Researchers argue for understanding the continuum of sexual behaviours of children and distinguishing between sexual age-appropriate exploration and sexual abuse, and behaviours that are problematic through to abusive.²⁵⁷ While there is concern regarding a young person internalising labels, the much more significant harm is in the impact of people around the child applying labels which can stigmatise or even demonise children and young people, such as ‘sex offender’ ‘perp’ and others.²⁵⁸ This is a compounding and intersectional issue for children and young people with disability, who already face stigma and discrimination due to disabling labelling. Outcomes for behaviour change are dependent on the quality and appropriateness of the support. The literature is optimistic about the potential for a level of success,²⁵⁹ and some evidence notes young people with disability require tailored interventions to achieve behaviour change.²⁶⁰

Noted in the literature is the importance of tailored responses to harmful sexual behaviours that are person-centred, relationship-based and address the child’s life domains.²⁶¹ In summary the key issues for which evidence is available are:

²⁵³ NSW Health IPARVAN p.35
²⁵⁴ (Hackett, 2014; Quadara, O’Brien, Ball, Douglas, & Vu, 2020)
²⁵⁵ (NSW Government 2018 PD2018_035 p 21)
²⁵⁶ (Balfe, Hackett, Masson, & Phillips, 2019)
²⁵⁷ (Hackett et al., 2019 ; Meiksins et al., 2017)
²⁵⁸ (El-Murr, 2017; Chaffin & Bonner, 1998)
²⁵⁹ (KPMG, 2014)
²⁶⁰ (Kjellgren, 2019)
²⁶¹ (Balfe et al., 2019)
The following sections of the report address the pathways, referral and access to services for children and their families; practices in services that support children who have engaged in problematic and/or harmful sexual behaviour, and workforce issues that affect capacity to do this work. The evidence for the report is sourced from a review of the research literature and interview with expert stakeholders (refer to section 1.3 for full description).

Interviews particularly highlighted issues associated with the online environment and noted this as an area for future investigation and delivery of programs young people with disability, particularly those with learning, or cognitive disability. Above all, stakeholders reiterated that children and young people with disability are children and young people first:

We need to recognise that children and children and they’re not adults and the trajectory for them actually is very good.

(Problematic and harmful sexual behaviours services provider)

### 5.1 Pathways, referral and access

Referral pathways for children and young people who have engaged in problematic and/or harmful sexual behaviours rely on recognising or understanding these behaviours, disclosure by the victim or witness and help seeking or referral by families, schools or others. Young people may come to services through the criminal justice system via police, school or family referrals, and child protection or children’s services. New Street report JCPRP Senior Health and Health Clinicians are the most likely source of referral, although anyone working with the young person can make a referral. The Child Abuse Royal Commission (CARC) noted an under-reporting of children with harmful sexual behaviours due to a lack of recognition, knowledge or understanding of the impacts of these behaviours.
5.1.1 Identifying and recognising problematic or harmful sexual behaviours

Research conducted into workforce perspectives on harmful sexual behaviour in the UK found that knowledge and skills across sectors working with children varied. Some practitioners were confident to work with children and others were not, with only 9 per cent confident in identifying harmful sexual behaviours.\(^{269}\) Children and young people with harmful sexual behaviours are often victims of sexual violence themselves, and so ‘children and young people occupy dual identities as perpetrator of abuse and victim of harm’.\(^{270}\) Responses are needed which mutually consider the support needed to respond effectively to the child’s behaviours of concern and the need to consider whether the child is in need of protection.\(^{271}\) The New Street model identifies three core areas of focus in their programs, safety, restitution and wellbeing.\(^{272}\)

There are several guides for recognising problematic or harmful sexual behaviours for those people working with children. Problematic or harmful sexual behaviours are defined on a continuum taking into account the young person’s age and development, and can be understood through the Traffic Lights Model.\(^{273}\) When looking at harmful sexual behaviours, it is important to consider whether the behaviours are developmentally expected; socially acceptable; consensual, mutual, reciprocal; and include shared decision making.\(^{274}\) While normative or abusive behaviours can be recognised, the complexity of identifying younger children’s problematic behaviours should not be underestimated.\(^{275}\) In interviews, stakeholders emphasised the connection to children with disability in discussing the limited information about both problematic and harmful sexual behaviour and support services among disability and support coordinators and a need for increased education across the sector to improve young people’s lives. Where opportunities arose to provide outreach and education, HSB providers conducted education sessions and described it as a strong strategy for both building awareness and connections. It was not a described as a systematic approach, and this is an area where practice might be extended (notwithstanding resource constraints).

The literature points to the impact of harmful sexual behaviours on families, and challenges for help seeking and support. In addressing the need for proportionate and timely interventions, the research notes it is common for professionals to find families and carers discourage expression of sexuality by children and young people with disability, and some prevent young people’s access to sex education. These attitudes have raised some concern about families being prepared to report or seek help when needed.\(^{276}\) Stakeholders in interviews supported these findings, and the need for increased inclusive sex and sexuality education. Some stakeholders extended this concern, pointing to issues of consent, where parents or families may refuse consent for children with disability to access sex education or other services connected to their child’s problematic and/or harmful sexual behaviours. For professionals this raised complex issues around heightened child protection risks in contexts where children were often trauma experienced.

Information about harmful and problematic sexual behaviour needs to be provided to the broader population. In interviews, stakeholders argue for improved education across the community, around issues of harmful sexual behaviours and sexual violence, sexuality and sex education for children and young people with disability and other preventative approaches such as developing healthy relationships, managing bullying and social inclusion.

### Improving access: Key priorities

**Training delivery**

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\(^{269}\) ‘Context and definition of ‘harmful’ can be open to personal interpretation’.\(^{270}\) (Clements, Ryder, Mortimer, & Holmes, 2017)\(^{271}\) (Hackett et al., 2019; The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)\(^{272}\) (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020, p. 68)\(^{273}\) (NSW Government, 2018 PD 2018_035 p 52, 66)\(^{274}\) (Clements et al., 2017; Hackett et al., 2019)\(^{275}\) (Hackett, 2010)\(^{276}\) (Smith et al., 2014)\(^{277}\) (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
5.1.2 Referrals
Knowledge of service supports among local service systems and families, community knowledge of supports and availability all affects if or when a children or young person is referred into specialist services. In some cases where police and the criminal justice system are involved there may be pre-court procedures or post-offence recommendations or automatic referrals. Young people in custody do not always have access to the interventions available to those in the community.277

The New Street evaluation noted referrals to their service increased once local services and professionals developed some understanding of referral processes.278 For a referral to be accepted at New Street the ‘behaviour must be confirmed by JIRT or Community Services and the young person must not be currently engaged with the juvenile justice system’.279 One model suggested frontline workers and local health services work using a matrix (framework) as they might for any other public health scenario or concern. The matrix would provide knowledge of available services and how to navigate them, including how to access qualified professionals who can facilitate contact for early assessment and referral to suitable services. where all frontline practitioners have access.280

The literature suggests a framework for accessing supports including referrals is integral to effective management and support of children and young people who have engaged in problematic and/or harmful sexual behaviours.281 This may occur through community contact and program visibility, close collaborative working relationships, integration with other children’s services and in some instances through co-location as is the case in some interstate and under 10 regional services. The research also notes deficits in mainstream services and some concern that children and young people with intellectual disabilities are not considered in policy and do not have their specific needs met in generic mainstream interventions for children and young people with harmful sexual behaviours.282

In interviews one service provider noted referrals are most likely to come through education and health services and in smaller communities by ‘word of mouth’. In communities with high visibility of practitioners’ roles, strong relationships with local schools and the broader community, increased local knowledge of services and made referrals straightforward. Informants noted several advantages of smaller communities in that communities were able to access information and seek support more easily. One service provider explained that his role in the community led to broad knowledge of his position where schools and families would seek out his help. He explained that in his position he spoke regularly at the local school and through his involvement in community education became a known person to families and a less threatening referral point. In one example, a young person with previous engagement with the service was referred (years later)
following incidents online. The existing relationship supported a straightforward referral and follow up services. Another service provider described how co-location with other children’s services led to ‘warm’ referrals and facilitated knowledge sharing.

Young people can have long waits (up to a year for a paediatrician) for clinical support. Service providers often set up other support structures to fill in gaps, drawing on their networks and skills of people involved with the child and using services that are available.

Sometimes it’s also about thinking about what information can I actually get now, what other pieces of information do I need but how am I going to figure out what I’m going to do here and now whilst I’ve got 12 months’ wait for that piece of this jigsaw puzzle or this piece? (Problematic and harmful sexual behaviours service provider)

Other stakeholders related disadvantages associated with smaller communities, particularly a lack of privacy about accessing support and timely access to specialist services. In regional and remote locations there are few services, limited knowledge about behaviours, and little relevant support other than periodic outreach programs. Service providers and policy makers also recommended more timely response in remote areas, noting that:

… by the time outreach workers get into these communities they don’t even want to talk about it anymore. (Policy maker)

When providing services for Aboriginal people, the importance of government and other organisations working to develop credibility and build a sense of safety for people to feel comfortable to seek assistance was emphasised by multiple stakeholders. One consumer representative noted that Aboriginal families are reluctant to seek support through official channels due to distrust of government, experiences of discrimination and fear of child removal. Several others emphasised that the responsibility for ensuring culturally safe services lies with government and the services system, and not with Aboriginal communities. Several stakeholders noted this could be supported by improving knowledge, increasing capacity building, including more Aboriginal staff to work with families and Aboriginal communities.

### Improving access: Key priorities

**Training delivery**

Trauma, intergenerational poverty, and disadvantage, looking at the child/young person’s context and developing strategies for support

Listening to children and young people with disability – addressing service gaps in knowledge and skills when communicating, child-centred methods with children with disability

**Resource development**

Easy to read, easy to understand, easy to discuss – communication tools for working with children and young people with disability that include non-verbal and pictorial resources

**Organisational support**

Young people’s complex needs, risk and ongoing support needs – where to go for help. Adopting the ‘no wrong door’ approach and referring across services to ensure children and young people have systems in place to improve the efficacy of interventions
5.2 Effective services and support

The literature on evaluated services for children and young people with disability is sparse, and principles of positive practice identified earlier also underpin any effective service support. The literature emphasizes that children and young people who engage in problematic and/or harmful sexual behaviours are children first. Interventions must centre on the needs of the young person through a holistic approach and, as a core response, address the young person’s vulnerabilities.\(^{283}\) This vulnerability and status as a child in need of support and protection was reinforced in interviews and articulated in this quote from a stakeholder:

\[\ldots \text{even in some of the most terrible situations that you hear about, you know, these kids are just kids.} \]  

(Problematic and harmful sexual behaviours services provider)

Children who have engaged in harmful sexual behaviours often have complex needs, and require support across service systems.\(^{284}\) Children and young people with disability and who have engaged in problematic and/or harmful sexual behaviours require more specific interventions based on their needs and additional vulnerabilities.\(^{285}\) The literature which focuses on young people with disability more commonly addresses intellectual or learning disability and Autism Spectrum Conditions (ASC), although within this field there remains a lack of evidence-based published research about successful interventions for these young people.\(^{286}\) Features of cognitive impairment that can increase risk for children and young people with intellectual disability are around issues with communication ability and understanding, psycho-social skills, planning and consequences, emotion regulation and friendships, understanding of, and influence by peers.\(^{287}\) A report commissioned by the Scottish government outlines service provision for children with harmful sexual behaviours through public health, prevention and risk, individual intervention and trauma-informed workforce, changing community culture and attitudes around gender, and psychological support for the individual and their families.\(^{288}\)

Service providers in the interviews emphasised the importance of looking beyond static descriptions of ‘vulnerability’ or ‘risk factors’ which are focused on deficits in children, and focus on the integration of the young person’s strengths and needs, which responds to the capabilities principle, family and carer support, and collaborative work across services to reinforce behaviour change. Both service providers and policy makers heavily stressed the need for interagency and holistic responses to address gaps and shortfalls which left children lacking effective support.

Providers of early intervention services for children with disability may be useful connections for providers in the harmful/problematic sexual behaviour domain. Often occupational or speech therapists by background, early intervention practitioners provide specialist support and intervention for children with disability, autism spectrum disorder, development delay and other associated impairments. Early intervention often focuses on four areas of children’s development: physical, cognitive, behaviour, and social and emotional. Multidisciplinary approaches can help children with disability to benefit with therapies tailored to their needs and interests.\(^{289}\)

Discussion of specific programs in the interviews mainly centred on Multi-Systemic Therapy, a program supported in research conducted for the Royal Commission CARC.\(^{290}\) However, service providers and policy makers were reluctant to endorse the program. In part this reluctance was due to service availability and the financial commitment needed to ensure its success and the inflexibility of the program. Other programs mentioned in the literature specific to people with

\(^{283}\) (Balfe et al., 2019)
\(^{284}\) (Hackett et al., 2019; Holomotz & Schmitz, 2018)
\(^{285}\) (Hackett, Phillips, et al., 2013)
\(^{286}\) (Schnitzer, G., Terry, R., & Joscelyne, T. 2020)
\(^{287}\) (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
\(^{288}\) (Raising Children Network, 2020)
\(^{289}\) (Shlonsky et al., 2017)
disability (but not necessarily children and young people) include the Good Way Model, \textsuperscript{291} Keep Safe, \textsuperscript{292} Forio, \textsuperscript{293} Safer lives, \textsuperscript{294} and Turn the Page. \textsuperscript{295}

While the literature outlines a range of models for working with children (aged under 10) and young people (aged 11-18), evaluation of positive practice within these models is limited. An overview of services prepared for NSW Health for children under 10, notes there is ‘little contemporary evidence to inform service delivery’ and any model needs to include ‘rigorous evaluation’. \textsuperscript{296} The evidence review noted none of the models focused on children with additional needs, and that any model would need to be ‘adapted to suit cultural needs’ in Australia. \textsuperscript{297} Adaptations include those that meet accessibility requirements identified in the principles – things such as approachability (how comfortable they felt approaching the providers), acceptability (how close a cultural fit the service was to their values) and appropriateness (how well the service location and operation fit their preferences). \textsuperscript{298}

5.2.1 Strengths based, timely and proportionate service responses

The literature emphasises that responses to problematic and harmful sexual behaviour in children with disability should be timely, proportionate and contextual, ranging from support in a crisis through to specialist services. \textsuperscript{299} Interventions are seen to need a focus on ‘the capacities of the person and what supports that person to succeed’, \textsuperscript{300} and for specific supports for young people with disability from marginalised communities. \textsuperscript{301} Developing an appropriate intervention and therapeutic support is underpinned by comprehensive understanding and assessment of a child’s skills and strengths.

Program effectiveness is associated with approaches that are child focused, look to the needs and context of the child, and in which services work together to improve children’s wellbeing, including addressing loneliness, social isolation and anxiety. \textsuperscript{302} The Forio approach provides intervention based on ‘warmth, empathy and support’. \textsuperscript{303} One Australian study points out that a proportion of harmful sexual behaviour has been identified through bullying and argues that there is a need to address this issue as a form of prevention. \textsuperscript{304} In interview, some providers mentioned that, when working with young people, other matters often take precedence in their lives and ‘the disability stuff can fade into the background’, illustrating the need for child-centred approaches in interventions.

The literature argues for strength based supports through the instigation of a safety plan for the child or young person to prevent and protect them from future or further harm. \textsuperscript{305} The young person’s safety plan needs to be developed in collaboration with clinicians and other service providers paediatrician, teachers, disability support, and supported by family, support workers and the broader contact networks. Given that children and young people with harmful sexual behaviours are often victims of sexual violence themselves, \textsuperscript{306} responses need to consider whether the child is in need of protection. \textsuperscript{307} The safety plan is particularly important where the victim is a sibling or lives with the child or young person. \textsuperscript{308} Recommendations should be made based on the

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needs of the child and family and the availability of appropriate local services. Safety plans can be developed through the four pillars approach, which includes ‘supervision, monitoring and control, interventions, treatment and victim safety’.

A child-focused approach addresses the needs of the child and their rights to safety, health, education, family, and to have a voice in decisions that impact on them. Observations emerging from the literature are the prevention and treatment of need to be guided by the rights based principles of the UNCRC and this can be achieved through a support and safety plan that provides ‘the right support at the right time from the right people’. This approach resonates in the interviews which overall emphasised that the child’s wellbeing and voice were critical in developing programs of support.

I think the voice of the child and their family is an essential part of the practice and the reason why the practice might be successful.

(Problematic and harmful sexual behaviours services provider)

One service provider explained the need for flexibility in service approaches and used a range of approaches to support young people.

I tend to take a lead very much from the way in which young people talk to me. I don’t have a therapy that starts at A and finishes at B, or D, or wherever it finishes. I don’t have that. I don’t have a linear approach. I like to have conversations. I like to learn from those. I like to use whatever mode.

So, I have a person at the moment, a young person who is 12, he loves to draw. So we have a conversation, and he will then take some time to draw that conversation, and that helps him remember it and he keeps his drawing, takes it with him, does some work, or he keeps it in my office, comes back. The drawings are his record of our conversation.

(Problematic and harmful sexual behaviours services provider)

The literature outlines holistic approaches in developing a safety plan which accounts for the activities and behaviours of the young person’s daily life and works with their interests and affinities. New Street services work with the young person and focus on ‘building self-insight and developing personal accountability’. Adapted methods need to accommodate the capabilities, understanding and capacities of the young person and benefit from ‘effective collaborations between clinical professional and the individual’s support network’. Resources can also be adapted to suit the capabilities of the young person, such as scaffolding information, using pictures or other modes of communicating, cartooning, developing emotional regulation, social storying and other social skills including prompting.

Interviews with service providers and policy makers confirmed the primacy of working with the child’s strengths in child-focused, relationship-based and holistic approaches. Stakeholders were united in stressing the importance of working with the young person’s strengths; flexibility in approach and services; and the role of the service provider in therapeutic work:

We should be looking for the young person’s strengths and abilities, rather than their deficits, and also we look for their positive qualities, and we do this in a systemic way with their carers and families, so that they’ll identify what are the qualities and things that they really appreciate and like about the young person, and we, from the start, should be working with them relationally because those relationships are life long and enduring within their families.

(Problematic and harmful sexual behaviours services provider)

We’re creating safety for them to be able to address issues that are really important for them. We need to be very creative and helping them being able to express those things,

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309 (Hackett et al., 2019 p. 42)
310 (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020, p. 70)
311 (KPMG, 2014 p. 2)
312 (Keller, 2016)
313 (Bateman & Milner, 2014, pp. 121-138)
because this is part of the territory and part of a generic layer of counsellor, you know, how do we facilitate that with a young person of every different type of ability.

(Problematic and harmful sexual behaviours services provider)

Stakeholders in interviews also identified the challenges of online safety which is not widely discussed in the literature, although mentioned briefly in a UK study, which noted that young people with intellectual disability are ‘particularly vulnerable to online grooming’ and there is a need for preventative education. One service provider observed that online safety is an increasing issue for young people (in this case with cognitive disability), and gave an example of a young person aged 17 who returned to their service, after some years due to issues related to online abuse. The service provider highlighted that young people, victims of abuse, or children who have engaged in problematic and/or harmful sexual behaviours, are ‘vulnerable in that online world’. Their view, accepted within the interview, was that services need to incorporate online safety into interventions and anticipate this issue for children as they get older. The service provider suggested that services:

… provide a form of purposeful maintenance [supporting young people on an ongoing basis as they move into teenage years] for young people with disabilities who are returning vulnerable to online exploitation.

(Problematic and harmful sexual behaviours services provider)

The literature notes many children present with complex and intersecting challenges in their lives, and a many have also had adverse childhood experiences. While the issue of assessment is not explored in the literature particularly for children with disability experiencing adversity, stakeholders across interviews discussed disability assessment and described how many young people present to services with a range of diagnosis, some of which appear to be inaccurate and unhelpful to the child (e.g. inappropriate medication or stigmatising labelling). It was the view of providers that these may have been provided earlier in childhood, for example to ensure the child can access learning support at school. Services providers noted the difficulty of ‘undoing’ diagnoses through processes of re-assessment, and most significantly, felt it had significant impacts on children.

The knock-on effect of a lot of that too, is that without a lot of that assessment being challenged or corrected or made accurate, there’s some real rusted on beliefs that form about young people, and the labels that they can carry that are inappropriate that people become quite stuck on.

(Problematic and harmful sexual behaviours services provider)

Keeping them … in that front seat is sometimes hard when you’re confronted with all the labels and other bits and pieces that are floating around them.

(Problematic and harmful sexual behaviours service provider)

Some services are co-located with developmental and other children’s services making access to assessments easier.

When kids come in sometimes with a diagnosis, or often, … with some ideas of vague terms that might have been thrown at the child at some stage, but not necessarily anything attached to that, we are able to access people from the developmental team and do that sort of cross-referral to look at that differential diagnosis, particularly with ASD and trauma, or look at mild intellectual disability or other sort of developmental concerns.

(Problematic and harmful sexual behaviour services provider)

315 (Franklin & Smeaton, 2017, p. 480)
316 (El-Murr, 2017)
Improving access: Key priorities

Training delivery

Child first – young people who have engaged in problematic or harmful sexual behaviours are often victims of bullying or sexual violence. The child’s wellbeing at the centre of intervention responses

Disability, assessment and person-centred interventions. Drawing on strengths, recognising trauma, and solutions-based therapy models.

Flexibility – what does flexibility mean when working with young people in a person-centred way? How can clinical and social interventions properly address the needs of young people with diverse disability?

Building on new skills, looking forward and maintaining safety - complexities and tensions for ongoing support as a person’s life changes and different challenges appear.

Resource development

Adapting resources for clear communication between workers and young people. Guides and resources to facilitate difficult conversations in an appropriate and accessible way

Organisational support

Working with what is available, drawing on networks of support. Adapting available resources and networks to support the young person.

5.2.2 Multimodal approach - support for families, collaboration

A holistic approach holds the young person at the centre, and this includes working with families and supporting family function.317 The New Street evaluation notes the value of interagency work, to support consistent ‘messaging’ of clinical interventions, engagement with clients, and address the needs of individual family members.318 Central to the New Street policies are a systemic and multi-agency approach, which operates under a service agreement ‘between the Local Health District in which the New Street service is located and the Sydney Children’s Hospital Network, to receive clinical direction, advice and support’.319 This includes developing safety plans,320 and assessing parents’ capacity to support the safety plan of the child,321 and support for engaging with services.322 New Street also has a memorandum of understanding with other NSW departments, Health, Community Services, Juvenile Justice, Police, and Education and Training.323

The impact on families whose young person has harmed can be challenging and parents may see the harmful behaviour as a reflection on their parenting and have concern for siblings who were victims of the behaviours. The literature argues it is important for young people to have opportunities to re-build trust and attachment relationships in their families.324

317 (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
318 (KPMG, 2014)
319 (NSW Government 2018 PD2018_035 p 1)
320 (Bateman & Milner, 2014)
321 (Hackett et al., 2019)
322 (The Expert Group on Preventing Sexual Offending Involving Children and Young People, 2020)
323 (NSW Government 2018 PD2018_035 p 135)
324 (Allardyc & Yates, 2013)
The Crime Commission notes that clinicians in Australia work with an ecological approach, and ‘strive to work closely with family or carers’ as the ‘only way to ensure therapeutic gains’. Stakeholders in interviews endorse these approaches and acknowledge the importance of working with families to reinforce therapeutic work and ensure timely changes in the young person’s behaviour.

I don’t want anyone coming here for such a long period of time, so lots of our work is also skillling up those parents and carers to support them in having those conversations as their child gets older and may start to navigate sexual relationships and being able to have the conversations to be able to do that need.

(Problematic and harmful sexual behaviours services provider)

Service providers and policy makers observed that while young people who have engaged in problematic or harmful sexual behaviours are diverse, many families include siblings, parents or family members with diagnosed or undiagnosed disability. Service providers explained that family capacity shapes their approach with the young person.

The parents of the children themselves may have disabilities, and that we need to have a way of understanding that and working with it.

(Problematic and harmful sexual behaviours services provider, and policy maker)

Building relationships with families and with agencies to support the young person through case management, consistency and collaboration are critical to successful interventions.

Improving access: Key priorities

Training delivery

Working with young people, working with their families, their networks and communities – young people in their context. How to manage and upskill young people’s networks to support positive behaviour change and social inclusion.

Reflective practice, cultural safety and learning from communities; check ableist assumptions and remove systemic barriers to support marginalised young people. Healing Foundation’s Four pillars - safety, identity, reconnection and trauma awareness.

Working with families, recognising diversity and complexity of families, including supports for others with disability. Respectful capacity building through rights-based approaches; New Street Model of practice – safety, restitution and wellbeing.

Organisational support

Building relationships with families and with agencies to support the young person through case management, consistency and collaboration.

5.2.3 Multiagency partnerships, support and collaboration

Multiagency collaborations which focus on the needs of the young person are universally supported across the literature. There are clear indications that successful collaborative
interventions for young people increase their well-being and support behavioural change, although key challenges exist cross agency relationships. In interviews, practitioners described collaborative practice in one area through a partnership with Relationships Australia, who are doing innovative work with children and young people with disability around sex and sexuality education.

The foundation of [that sex and sexuality education] work being relational and having a connection base … is very, very helpful, because it’s such a touchy area and an area that kind of starts to infringe a little bit on rights to communication and access and that kind of stuff, particularly as you’re dealing with that older end of adolescence who may even be past the age of 18, with or without guardianship orders.

Service providers who were part of child and community development hubs were well known across different sectors. This facilitated a cross sector approach and service providers could work with services that already exist around the young person. Co-location with other services also worked well to support collaboration.

Other research recognises educational institutions are an integral part of support for young people and note the importance of positive engagement in education for supporting behavioural change and promoting positive life outcomes. Interviews maintained that to be effective, support services must work collaboratively and incorporate the young person’s daily world in an ecological approach working with family, friends, school, and broader community as far as possible.

[We] work in the context of that young person and their system. So, we do work very systemically because we recognise that we only see these children for one hour a week. When we’re thinking about longevity of our work, we know that these messages, this work is going to need to be reinforced with these young people for a duration of time.

Young people who have engaged in problematic or harmful sexual behaviours are a ‘disadvantaged and disempowered group’, and a population ‘that falls between service thresholds’. Multiagency approaches can prevent young people falling through these ‘service thresholds’. Interviews support multiagency approaches and working in teams within the service and teams across different sectors for the benefit of young people. Stakeholders described some successful team partnerships, and models of multimodal and interagency work, including NSW government programs with New Street Services and Mental Health, Whole Family Teams, a partnership between Child Protection and Health, Alternate Care Clinic, and GOTIT program (policy maker). However, several policy makers, noted the introduction of the NDIS had led to changes and challenges, and it was important services build teams to work across sectors (problematic and harmful sexual behaviours services provider).

Case management can support interagency collaborations. Case managers oversee the range of services the young person is engaged with and support their families. In the absence of a case
manager, one service provider explained they stepped into the role to ensure the child had a team around them to ‘champion and support’ them.

An opportunity to explore in future practice is planning for children and young people with disability that is developed jointly by practitioners expert in problematic and harmful sexual behaviours and practitioners expert in children and young people with significant disability. This is one way to extend the capacity of existing New Street service provision to support children with higher and more complex support needs.

Improving access: Key priorities

Organisational support

Finding common ground – learning from each other. Working with person-centred approaches to promote interagency supports and cross sector collaboration education, health, child protection, and justice

Building networks with other organisations and participating in training and professional development

5.2.4 Education and training to improve and develop workforce skills in trauma informed practices

Literature about workforce skills for people working with children and young people with disability who have engaged in problematic or harmful sexual behaviours is limited. While the literature looks to programs of support, it does not highlight workforce skills. As a way forward and noting this gap, this report concentrates on the skills, training and education identified in the interviews.

The nature of the conversations in the interviews highlighted that practitioners need skills, flexibility, capacity and confidence to support and work with young people with disability who have engaged in problematic or harmful sexual behaviours. In these discussions, stakeholders consistently noted the need for integrated services with timely and ready access to specialist support for assessment. Workers need to understand the diversity of disability, disability assessments and in some instances be able to de-construct them. Adaptability of skills to adjust to the learning styles and skills of children and young people with a range of support needs was a key skill development opportunity for a workforce which was already highly skilled in working with children and young people who have engaged in problematic and harmful sexual behaviour.

Speaking broadly about access to services, several policy makers noted it is important Aboriginal workers and clinicians are working in programs and building relationships of trust with the community. Barriers to programs for communities which have higher rates of disability can be overcome through mentoring members of communities to work with service providers. One example discussed in interviews is the GOTIT program, which adopts ‘an envelope approach’, targets children aged 5-8 with conduct disorders and multiple needs. The program has developed cultural competency to work with Aboriginal children.

The literature and interviews make the case for improved sexuality and sex education for children and young people with disability, and competency in delivery of the information. Interviews with service providers, policy makers and academics noted an urgent need for mainstream resources to be adapted for young people with intellectual or other cognitive disability. This included worker competency to communicate in plain English, confidence in speaking literally and clearly about sex (disability and sexual assault services provider, disability policy maker, academics). People working in the field must step back from their assumptions and work with the young person’s capabilities. One disability policy maker explained workforce skills must include understanding and working with a range of language skills.

Language and being able to adjust the way they [service providers] deliver and interact to accommodate the disability and understanding that there needs to be a level of flexibility
and that the communication styles need to be different to encompass that. But also acknowledging that – things that are an assumed knowledge are not – can’t be assumed in the disability sector.

(Disability policy maker)

There is also a need to increase understanding of problematic and harmful sexual behaviours in the context of bullying for people working with children with disability.332

Service providers noted they benefit from opportunities for networking and information sharing, through training, professional knowledge exchange, conferences among others. Networking and sharing information were valued as ways to improve knowledge and develop skills.

Improving access: Key priorities

Training delivery

Talking about sex - sex and sexuality education – for people across all sectors working with children and young people with developmental delay and limited language.

Working effectively with children and young people with cognitive disability (children with intellectual disability, autism, acquired brain injury)

What is safety? - online behaviours, social participation and talking about consent in a concrete way.

Looking to the future, developing knowledge and skills in the present - understanding violence and abuse, and healthy relationships education for:

- Children and young people with disability included in mainstream sex and sexuality education, adapted resources,
- Sex and sexuality education for people with disability
- Disability and support workers
- Families of people with disability
- Networks of support

Resource development

Online training resource – SECASA Dealing with Danger

Clear information about how HSB services can respond to the needs of children and young people with disability

Organisational support

Making networks, sharing information, making opportunities for resource and knowledge exchange including communities of practice.

332 (Meiksans et al., 2017)
Part III: Co-design and co-production

The principles and practice of co-design and co-production are outlined in this next section. These prepare the groundwork for developing the co-design framework, the next stage of the ECAV project.

6. Co-design and co-production

Co-design is framed optimistically as a process for governments and service providers to work with communities and service users in a more equal partnership and dynamic relationship to understand issues and create knowledge for change.\(^{333}\) Co-design is seen as a process that can produce different knowledges and lead to social transformation.\(^{334}\) Underlying co-design are principles to ensure meaningful citizen engagement between stakeholders and the assumption that the ‘provider and user can work actively together in the delivery of a service’.\(^{335}\)

In the context of adults with disability who experience sexual assault and children and young people with disability who have engaged in harmful and/or problematic sexual behaviours, co-design is sensitive and needs to be approached carefully in order to avoid traumatising or re-traumatising people with disability and their families. This has received minimal attention in the academic literature to date, beyond calls for better inclusion of women with disability in issues that shape their lives. A small number of studies have taken a co-design approach with women with disability in research on domestic and family violence.\(^{336}\) These studies have found that it was personally important to the women to be involved; that building relationships with researchers and peers in the group over time was critical in deepening and extending contribution; that demonstrating the effect of women’s contribution to change in the projects was essential to gain continued commitment; and starting from a place where women were not currently experiencing violence or abuse mattered. Aligning trauma-informed practice with co-design strategies may be a helpful way forward in shaping co-design approaches.\(^{337}\) The following principles are drawn from the Disability Innovation Institute UNSW paper, Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability.\(^{338}\)

### Principles of co-design and co-production

**Power sharing** – projects acknowledge and manage power differences, share responsibility and have methods in place to ensure shared responsibility and collective control and ownership of the project.

**Diversity** – different expertise and skills are brought together and all voices are respected and valued.

**Accessibility** – barriers that prevent participation are addressed and including physical and information accessibility

**Reciprocity** – co-production is mutually beneficially for all participants and stakeholders.

**Transparency** – there is a shared understanding of the goal of the co-production, and recognition of each participant’s skills, with open communication that builds trust in relationships.

**Flexibility** – co-production needs to adjust to the participants’ needs, skills and resources.

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\(^{333}\) (Beebeejaun, Durose, Rees, Richardson, & Richardson, 2014)

\(^{334}\) (Beebeejaun et al., 2014, p. 40)

\(^{335}\) (Crompton, 2018, p. 220)

\(^{336}\) (Dyson et al., 2018; Robinson et al., 2020a, b)

\(^{337}\) (Jackson & Waters, 2015)

\(^{338}\) (Strnadova, Dowse, & Waitfern, 2020)
These principles resonated in discussions throughout the interviews about how co-design has been applied in their work in sexual assault and harmful and problematic sexual behaviours contexts. Although not all participants were familiar with the process of co-design, many spoke about practices of co-production and how they lead to service improvement. A consistent emphasis from stakeholders in the interviews including consumer groups, service providers, policy makers and academics was that co-design is underpinned by recognition, respect, reciprocity, trust and clarity. The heightened sensitivity of this context made this relational underpinning even more important.

People in the interviews who had experience in using co-design viewed it as an ongoing process, built on developing respectful and trusting relationships. They noted it was important for expectations to be clear, to work collaboratively and build on each other’s skills and knowledge.

The Co-design for Community Inclusion report found skills of collaboration, empathy and shared goal for end users support the co-design process. The National Disability Insurance Agency 2015-19 corporate plan outlines eight principles which reflect those mentioned above and include several prescriptive processes. These additional factors related to co-design processes as ‘holistic and user centred ‘ with representation across diverse stakeholder groups’, clear and timely follow up, and sharing findings to support the next stage of the project. These factors are included within the six principles identified in Doing Research Inclusively.

6.1 Co-design, co-production and working together

The literature and interviews provide insights into how these principles may work in practice for policy makers and service providers wanting to use co-design and co-production. The Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability outlines key methods and approaches for co-design with people with disability. Representative and collaborative leadership and establishing shared understanding of goals and expectations is important when setting up a project. Commencement requires in the first instance budgeting and resources, inclusive agenda setting, leadership, and recruitment of co-researchers/designers.

The Co-design toolkit, designed by the People with Disability WA was developed to ‘engage, connect and co-design with people with disability’. The toolkit outlines steps for productive relationships and projects and provides specific tools for mapping the process.

People with disability are part of each step. The toolkit steps include: engage – with people with disability, plan – what participation might look like, explore – understandings and concerns, develop – ideas for improvements; decide - on priorities and how to change them, based on insights from people with disability about services; implement change. Other studies have minor variations of these six fundamental steps.

Co-design with women with disability around violence and abuse subjects has been conducted to high standards by gender-driven peak and systems advocacy organisations. WWDA’s new ‘Our Site’ online rights-based resources and information site was made by over one hundred women and girls with disability. By broadly promoting the project to their large membership and an ‘opt in’ approach to co-designing all elements of the project, the component on safety from all forms of violence invited participation from women who self-identified as resilient around these topics and wanting to engage. Practical and emotional supports were put in place before, during and after all meetings. This project was also peer led and peer driven.

The development of 1800 RESPECT Sunny App and strengthening training and skills was underpinned by co-design with women with disability (refer to p.38 for description). The co-design
process included using trauma-informed approaches to inform the project design; making counsellors available before, during and after all engagements around the project development activities; taking advice from specialists on how to make consultation processes accessible to women with disability; and building a longer-term relationship with women over time, rather than short, one-off consultation.

The interviews provided specific examples of co-design in developing resources and services for people with disability and these are explored below.

6.1.1 Building relationships, mutual trust and rapport
Support for relationships is important if consensus and shared goals are to be achieved. Building a mutual respect and rapport with the co-design team includes planning and ensuring members have the support they need to participate. This will include working with existing networks and ensuring appropriate supports to accommodate any additional needs; and builds on the well-recognised resilience of people with disability. Training all stakeholders in co-production at the same time can support shared outcomes, build team goals and develop a sense of trust as relationships develop over time.

Co-design is deeper than consulting with people with disability. To build innovation and new directions, it is important to be able to ‘follow the lead' and direction of participants, to be able to jointly uncover what they themselves identify that they need in place, the supports that they already have and trust, and the opportunities for development that arise from this. This is important for strengths-based approaches that recognise resilience and resources of people with disability and/or people with lived experience of sexual violence and share power (see p.63).

Improving access: Key priorities

Training delivery
Learning from the experts – what does inclusion and participation mean for people with disability
Reciprocal relationships - shared learning spaces and collaborative approaches to co-production
Shared communication skills – working with communication aids, interpreters and translators, talking mats

Resource development
Communication aids, interpreters, talking mats, pictorial communication supports

6.1.2 Shared language and communication processes

The importance of language is brought into high relief in this cross-sector and cross-disciplinary project, where multiple perspectives about disability, sexual violence and harmful and problematic sexual behaviours are in play. There is significant potential for language to cause offence and shut down dialogue, and co-design is a productive avenue to minimise the potential for this.

There are some useful toolkits to guide practice in this space. The NSW Agency for Clinical Innovation Co-design guide has useful processes for developing role clarity and purpose, establishing communication processes, and taking a trauma-informed approach.346 The UK Social

346 (NSW Agency for Clinical Innovation, 2019)
Care Institute for Excellence also has an extensive suite of resources on co-design and co-production in a range of relevant contexts.347

One service provider explained that during the co-design process they produced a document that outlined any concepts, jargon or service language that was particular to the project. This helped to build shared understanding of the project and reduced any confusion among stakeholders.

Improving access: Key priorities

Resource development

Unpacking key ideas in the project – developing a process to ensure shared meaning and shared language in the project

6.1.3 Facilitate participation through training and supports

Representation from across the community supports the work of co-design through ensuring diverse voices and experiences are heard. Facilitating representation may include adapting methods for participation, making easy read documents, for example meeting minutes; preparing reports and notes ahead of time to allow people time to read and respond; working with support workers (with the person’s consent); making contact with people prior to meetings to ensure understanding of reports and enable participation (disability and sexual assault services provider).

People with disability stressed in consultation the importance of understanding that all participants are not starting from the same ‘even playing field’, and being alert to signs that people may be feeling overwhelmed by the speed of processes, jargon, subject matter or emotion. They provided examples from their own experience of training delivered by people with disability as lived experience specialists as being helpful in contributing to co-design success. There was multiple practical reasons for this – the slower pace; the reduced amount of jargon, the clearer framework for events. Over and above this, however, was a much more important factor – the connection that co-facilitators could make as someone who truly understood these experiences.

A consumer representative with experience in developing and testing resources through co-design said addressing accessibility and adopting multiple methods for participation was critical for inclusive co-design.

Whether it be [the requirement] to meet someone in person rather than doing interviews over email and things like that. Or getting an Auslan interpreter or making sure we’re sending out accessible Word documents rather than PDFs. Writing things in easy English … there’s lots of different ways. (Disability consumer group)

Co-design projects concerning violence or other distressing content require ongoing commitment and responsibility for the wellbeing of people involved. This can be addressed through structural supports initiated from the beginning of the project.

Before you even start, when you’re doing co-design you link them into a support centre …particularly where anything is around violence – counselling and emotional wellbeing supports need to be formally put in place from the beginning

That you would go into that role formally and that there’s a formal debriefing at the end of every kind of conversation and input stage. (Consumer group representative)

347 (Social Care Institute for Excellence, 2020)
Organising practical support for participation is also important. Stakeholders in interviews explained that sometimes co-design means knowing someone needs transport so they can attend a meeting and facilitating that.

The NSW Intellectual Disability Rights Services has co-designed and co-facilitated training in a range of justice and violence areas for many years. Processes this service uses to support and sustain co-designers and trainers includes payment for work (particularly full employment); development of ongoing relationships over time with trainers; investment in building capacity and knowledge in co-trainers with and without disability; and access to informal and formal support in the event of distress for participants in training and facilitators (including psychological and legal advice and assistance).

### Improving access: Key priorities

**Training delivery**

- Developing inclusive and collaborative leadership skills - working with and developing capabilities
- Speaking up, speaking back and listening – understanding power dynamics, power structures and ableist assumptions

**Resource development**

- Actively plan for resources to support people who may experience trauma through participation in co-design

**Organisational support**

- Rights-based thinking - reciprocal relationships, working with diversity and learning from each other

6.1.4 Diversity education and tailoring responses and support.

One disability and sexual assault services provider described co-design in a project working with people with acquired brain injury. To facilitate participation the services provider took time to learn how to work with people’s capacity. They also explained allowing enough time for the project to be respectfully inclusive. To ensure full participation, information was shared prior to meetings and each meeting began with restating the purpose and goals of the project and that meeting. The service provider sought expertise and knowledge about ABI from advocacy groups to learn how to tailor their approach.

*How do you know? Things about them getting tired and all of that kind of stuff. How do you prompt stuff without - you know, without frustrating them and making the person feel that you know they forgot and all of that? So just having that really tailored approach to each of the women was really important and it worked. It was hard work but it worked.*

*At the end of the process participants with ABI had developed their capacity and confidence to speak up and they (the service provider) had developed confidence in listening and supporting participation.*

(Disability and sexual assault services provider)
Improving access: Key priorities

Training delivery

Understanding ability – working with strengths and respectful systems to ensure inclusive participation

Resource development

Allow adequate time and supports to accommodate participation needs, including but not limited to training for participation and expectations

6.1.5 Listening to people with disability across the community

Listening to people with experience of disability provides insight and knowledge of their lives. Through acknowledging the expertise of people with disability, understanding community protocols and listening, co-design is an opportunity for policy makers and practitioners to learn from service users. Identifying appropriate staff to facilitate these processes is also a key task – ensuring that an intersectional approach is taken to promoting the perspectives of people with disability. This might mean that facilitators are sought who have expertise and experience (ideally, lived experience) across disability and other domains of interest to this project – Aboriginality, cultural and linguistic diversity, rurality, LGBTQI+, and so on.

Co-design was viewed positively, where it is led by people with disability in terms of development and delivery. Interviews with consumer groups emphasised repeatedly the need to recognise, listen, and pay attention to people’s expertise.

Each of us are the expert in our own lives and we respect that our peer is the expert in their lives. (Consumer representative)

This view was supported across the interviews. As one policy maker explained, listening and following community protocols support providers to meet community’s needs.

I think just from an Aboriginal perspective, and you would have heard all of this before, just making sure that we have people going out into community and yarning with Aboriginal people in community. Yarning with the Elders and making sure that it’s done in a really respectful way. When we do go out into community and sitting down with Aboriginal people, have those discussions led by Aboriginal people. (Policy maker)

Improving access: Key priorities

Training delivery

Understanding community protocols, and listening across difference – acknowledge and learn from expertise of people with disability

346 (Iudici et al., 2019; Pestka & Wendt, 2014)
6.2 Addressing challenges for inclusive co-design

Effective co-design relies on processes of participation and co-production that are disability-inclusive, that work to remove obstacles and barriers to participation, and facilitate a range of ways to participate that are based on a person’s capacity, strengths and preferences. Deeper and richer than consultation, co-design involves developing mutual understanding of the expertise that is brought to the ‘table’ by people with different stakeholder roles, and finding ways that these perspectives and expertise can be used to shed new light.

In the conduct of this needs assessment, advice on co-design with people with disability was sought from peer-led peak and advocacy organisations about how best to consult with people with disability about co-design and about sexual violence. We received consistent advice that the risks of re-traumatising people were such that we should avoid directly asking people about experiences of violence, and instead focus on experiences of seeking support. In most of the consultations, people with disability themselves raised help-seeking in sensitive contexts, including around violence, but only once trust and rapport was well established.

This is consistent with the findings from the limited body of academic research using co-design approaches with women with disability, which found that relationship-based co-design groups led to advice on interview guides which avoided direct lines of questioning to women with disability about violence. The interviews nevertheless gathered data about experiences of violence, as research participants offered their experience once they felt confident in the researcher’s interest and capacity to hold their story with some integrity. The key message from this research is that women and children need to be given the authority to decide when they share their stories.

Challenges of co-design around sexual violence lie in the nature of violence experienced by many women with disability; the accessibility of information about violence, abuse, neglect and exploitation; and ensuring adequate resources to avoid tokenistic consultation. The high rates of violence and repeated incidence of violence experienced by many people with disability mean that it is likely that women or children in a group are likely at some point to either experience fresh violence, or be troubled by historical experiences of violence (perhaps due to subjects under discussion). Access to effective support, both for justice and psychological support, is important for these women and children if they wish to take it up.

Accessible information is improving, but a lot of the accessible information in the field focuses on outlining different forms of abuse, rather than providing pathways to support. Some women with intellectual disability have said they find material with photo illustrations depicting violence triggering and unhelpful. Attention to the purpose of accessible information is needed to ensure that it is well targeted and directed towards productive outcomes for women and children to avoid unnecessary trauma in co-design processes. For example, presenting the results of a gap analysis of resources to the group and focusing on where to direct attention with new resources would avoid dwelling on how difficult resources are that depict abuse in detail.

Challenges for co-design begin with dismantling power structures, and while difficult to be fully transformative in this context, this can be operationalised through accounting for power and balancing policy priorities with service users’ needs. Being open and transparent about influence and capacity to inform decisions in policy and service development is an important element in building authentic relationships. This links to sharing of power and is a very important aspect of trauma-informed approaches. We reduce potential trauma by being clear about roles and responsibilities, and not misrepresenting influence and outcomes.

Developing processes to accommodate different worldviews in co-design activities is another way to balance power, by creating respectful and culturally safe spaces, ‘principles for engagement’, building trust and so on.

349 (Trischler, Pervan, Kelly, & Scott, 2018)
350 (Robinson et al., 2020 a,b.; Dyson, et al, 2018)
351 (Robinson, 2014)
352 (Jackson & Waters, 2015)
Co-production takes time and resources to be successful. The literature notes other challenges in co-design include dominant reliance on text-based resources for communication, privileging some voices and problems accommodating different worldviews. Failure in communication around shared goals can also lead to misunderstanding. Allowing adequate time for planning, accessible activities, conversation and resources to support participation, role clarity, support and collaborative leadership are all strategies which can address the known challenges to disability-inclusive co-design processes. The toolkits and resources referred to on p. 59 offer practical ways to approach each of these areas of practice.

Part IV: Recommendations

7. Recommendations

The project recommendations aim to activate the principles and practices identified in this literature review and interviews. These are pitched at a level to initiate change in practices and are also threaded to the practice principles for accessible services identified in Section 3 of the report. They also connect directly to the implications for training delivery, resource development and organisational support (collaborative approaches) identified in the evidence (see Appendix).

7.1 ECAV role in improving integrated cross sector collaboration

By virtue of its position as a trusted education provider, with existing collaborative relationships with other key central health organisations including the NSW Ministry of Health and NSW Agency for Clinical Innovation, ECAV can play a valuable role in improving integrated service delivery between NSW Health Sexual Assault Services, New Street Services and wider VAN Services.

ECAV can promote and support more effective cross sector collaboration between NSW Health Sexual Assault Services and New Street Services and disability sectors to improve the use of sexual assault services by people with disability. These collaborations would focus on providing a holistic strategy approach for children, young people and adults with disability and include referral pathways (through the ‘no wrong door’ approach), therapeutic interventions, addressing housing, financial support, cultural support, medical care, mental health or drug and alcohol support etc.

The siloed approach to supporting people with disability is well established as an entrenched problem. Identifying and addressing creative ways to overcome these disciplinary boundaries is a priority in overcoming resistance from gatekeepers to children, young people and adults with disability benefitting from sexual assault services support, and interventions for children and young people who have engaged in problematic and/or harmful sexual behaviours.

ECAV can lead solutions to breaking down siloed services through delivery of localised integrated and interagency training opportunities that will enhance knowledge of existing services and referral pathways. Offering education and training outside of the sexual assault sector is one strategy to open the door to collaboration. Knowledge of the composition of workforce and service user populations can inform priorities for ECAV when targeting training opportunities.

Another is to build communities of practice which invite multi-disciplinary collaboration across the range of domains where people with disability commonly interact, including education, health, justice, and specialist services such as NDIS and disability support agencies.

A focused activity to build referral pathways is for ECAV to support SAS and NS include a focus on strengthening referral pathways. This may be framed around supporting SAS and NS providers to include this in annual service planning, and providing support to them to reflect on current service
use, identify key contacts in local communities, engage them in service design and referral pathway work.

### 7.2 Promoting disability inclusive service design

Statistics from the prevalence data suggests that there is a statistically high likelihood that a person with disability ‘should’ present – but we know that they don’t, not because they don’t experience sexual violence etc but because they are frequently an afterthought in service design and therefore services are not inherently inclusive of their needs. Several key issues emerge from this:

- Encouraging and supporting inclusive service design assumes disability in potential clients rather than considering it an ‘exception’ – and this can lead to fundamental design principles that benefit all clients and lead to ‘disability-ready’ services.
- Service design thinking is a very useful framing for reconceptualising approaches to build inclusive services. The five principles of the framework are that services are user centred; co-creative; sequenced; evidenced; and holistic.

We recommend ECAV incorporate inclusive service design thinking into training for managers of sexual violence and harmful sexual behaviour services. This training could support and encourage co-design with people with disability; lateral thinking about creating inclusive environments; generate a holistic approach that avoids diagnostic approaches to disability; embed consideration of accessible service engagement, clinical outreach and resource use from the outset; develop responsive and strength based clinical practices and respond to localised priorities.

### 7.3 Embedding co-design

ECAV has a 30-year history of embedding co-design principles into their work with Aboriginal communities through the long-term establishment of an Aboriginal Communities Matter Advisory Group and Aboriginal Training Portfolio that develops and delivers state-wide community and worker programs. ECAV also applies community-based participatory research methodology to related violence projects established to develop practice-based evidence through close collaboration with people with lived experience and relevant practitioners. This knowledge and experience can be leveraged and its principles applied to its future work with people with disability.

There are strong opportunities in this project to work in collaboration with people with disability together with the disability and sexual assault services sectors, (sexual assault services and services for children and young people with problematic and/or harmful sexual behaviours) in

- Co-designing foundational training, ongoing professional development and an effective supervision model
- Co-designing resource development for children, young people and adults with disability and their families and carers; as well as the disability and sexual assault and harmful sexual behaviours sectors
- Co-designing the development of communities of practice, through state-wide practice forums and roundtables to build and strengthen the Sexual Assault, New Street and wider VAN workforce and local area services.

All initiatives are to embed the leadership of people with disability (for example, consumer-led governance models, consumer co-facilitation and consumer involved supervision). We recommend that ECAV establish a Co-design working group with at least three disabled people’s (peer-led) organisations partnered in this project to develop a Co-design Framework, and consider the value of an accessibility audit tool for sexual violence and harmful sexual behaviour services. Other relevant stakeholders should be included as appropriate. Their role will be to advise, critique and strengthen co-design principles and practices; consider potential from the work in practice for the

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357 (Stickdorn & Schneider 2012)
disability context; and build on existing practice in disability training, resource development and collaboration.

7.4 Education for leadership and collaboration
In addition to the targeted strategies recommended in sections four and five for building skill in workers and managers in NSW Health therapeutic services, this needs assessment demonstrates that education to develop leadership capability is needed to drive change across sexual assault and harmful sexual behaviour services.

Building specialist skill and leadership capability in key areas has been shown across many fields to improve quality in support for people with disability.

ECAV should give consideration to developing a leadership development program to build workforce leadership for NSW Health SAS and NS Services around disability inclusive practice in the following areas:

- Building state-wide and local partnerships with disability providers/peak bodies
- Driving NSW Health and interagency policy reform
- Promoting and supporting staff to improve skills and engage in flexible clinical outreach,
- Engagement and counselling with people with disability
- Establishing and encouraging ongoing supervision and peer support to develop and contribute to practice informed evidence in this area
- Implementing co-design framework and audit tool within VAN services and across LHDs/Networks.

As with all of the initiatives, this should be co-designed with people with disability.

7.5 Building and maintaining high quality resources
Resources facilitate access to services and can be used by services providers and users to explain and understand elements of service provision and practice. Making resources accessible to people with a diverse range of disabilities is essential for accessible service provision. A wide selection of resources has been developed about violence and sexual violence for people with disability. These vary significantly in quality and availability. One substantial barrier is reliability of access to resources – when project funding finishes, so does access to resources.

- Establish an accessible Information and Resource Database under the ECAV Disability and Sexual Assault Information and Resources Databases online share-point funding stream.
- Ensure key resources are available in a range of formats, including easy read, plain English358, video, multi-language and accessible to screen-reader online formats
- Undertake an audit of existing resources and consult with consumers and stakeholders to determine gaps, preferred formats, and future development of useful resources: e.g. supported (warm) referral, how to persist in getting what you need, managing your feelings, getting support from workers and your own networks at the same time

A list of resources is appended. We have included those which are high quality and from robust sources (likely to remain in use for some time). We strongly recommend that ECAV check with the provider individually before recommending their use to ensure continued access is guaranteed.

We recommend making use of existing resources where possible, particularly those which have been co-designed with people with disability.

358 Easy read documents use very basic language in short sentences with pictures to illustrate key concepts. Plain English documents break down standard English documents into clearer language but are not as simple as Easy Read.
7.6 Visibility of services and expertise within the sector and across the community

- Develop promotional material to help sexual assault and harmful sexual behaviours services explain their role and what they offer in an accessible format for people with disability
- Develop community education resources for sexual assault and harmful sexual behaviours services and disability providers to partner in raising awareness of sexual assault and harmful sexual behaviours to increase engagement with disability community. Consider developing a matrix which local services can adapt to develop pathways to support for all sectors (a local ‘no wrong door’ approach)
- Community engagement and public education
- Build capacity for disability providers to identify and respond effectively to sexual violence
- Build capacity for Sexual Assault and New Street services to deliver clinical outreach and effective community engagement strategies with disability communities
- Build capacity and provide training for workers to understand and use existing frameworks for information sharing across sectors

7.7 Evaluation

Ongoing and systematic evaluation of services support the development of evidence-based practices.

Evaluation is key to maintaining positive practices that reflect the needs of people with disability and children and young people with problematic and or harmful sexual behaviours. The literature notes a lack of systematic evaluation in this field and has long supported the need to capture and use data to implement positive change and develop services. Inclusive evaluation of the ECAV project which meaningfully involves all stakeholders, including people with disability, will be important in effectively measuring depth and quality in initiatives. An evaluation framework is the next phase of ECAV’s work.

The next stage of the project will work to consolidate and operationalise the recommendations from this needs assessment into an implementation plan to inform the Sexual Assault Services and New Street Access Strategy.

\[359\, (Didi et al., 2016)\]
PART V Appendices

8. Improving access: Key priorities - summary of implications for workforce capability building to improve accessibility

This section provides a consolidated list of the implications for building workforce capability. These recommendations are derived from the findings from the literature and the interviews.

The implications make clear the skills and knowledge needed for an effective and inclusive disability strategy.

8.1 Summary of key priorities for improving access in sexual assault services

8.1.1 Training delivery

Disability awareness

- Enabling service providers to apply a human rights framework in sexual assault, health, education and justice services
- Understanding disability – the diversity of people with disability who may access sexual assault services. Primary disability types, visible and invisible disability, undiagnosed and unrecognised disability, having sensitive conversations about disability
- Self-reflective practice – checking power, privilege and ableist assumptions

Improving referral pathways

- Building pathways to reach people with disability in multiple ways – understanding the diverse service and life pathways used by people with disability.
- Building cross-disciplinary pathways for referral and information sharing

Disclosure

- Disclosure for people with disability: identifying and recognising sexual violence, sharing knowledge, supporting disclosure and attention to clues, behaviour, non-verbal signs.

Improving relational and cultural safety

- Making safe spaces for people with disability in communities who are less heard (Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, people in closed settings)
- Working within a person’s context and cultural needs – with peer support and mentoring in Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and with LGBTI+ communities.
- Building cultural safety: Feeling welcome, communicating support, developing rapport. How services providers can communicate a non-judgemental, warm and welcoming environment.
- Warm referrals and supporting people with disability to move from referral into active support

Practical skills

- Communication: working with communication aids and interpreters, talking about ‘hard to discuss’ subjects, concretising concepts, that is using literal and unambiguous language for people with intellectual and cognitive disability.
- Supported decision making and consent – skills and strategies for supporting decision making for people with disability, with and without communication aids, including children and young people. This activates human rights and draws on expertise of people with disability.
- Adapting counselling practice for accessibility: simplifying key concepts; being clear in expectations; giving accessible follow up with support
• Working with supporters to hold the person with disability at the centre and build their autonomy
• Building confidence in working with people with communication impairments, people with significant and complex support needs
• Understanding person-centred planning and the role of a SAS worker

Trauma informed support
• Using trauma informed approaches through a disability lens as the foundation for inclusive services.
• Using and adapting person-centred and relationship-based support in times of crisis.
• Safety planning for people with disability: how to support and structure safety in particular circumstances (e.g. where a person lives in a group home where there no alternative accommodation is available)
• Working together – developing a support plan. Consistency, availability, flexibility, strengths and capacity based (working with strengths and abilities).

Co-design
• Peer led training on priorities of people with disability for crisis support for communities of practice, networks

8.1.2 Resource development
Information about sexual violence
• What is sexual violence? Resources for sex and sexuality education in multiple formats for diverse audiences

Information to support service use
• Screening for sexual violence with people with high support and communication needs
• Guides about using sexual assault services in a range of alternative formats (easy read, video, community languages).
• Advice from people with disability about their priorities for support in times of crisis
• A toolkit of resources to support effective communication
• Communication supports, aids, skills, (e.g. Talking Mats, Traffic Lights)
• Adapting resources – working with a person’s capacity and ability. Examples include ‘single session’ counselling for people with intellectual or cognitive disability, ‘concretising concepts in counselling’ (disability and sexual assault services provider)
• Understanding systems from the vantage point of people with disability

8.1.3 Organisational support
Referral
• Enacting ‘warm referrals’, sharing knowledge about services and systems for service users.

Improving service integration
• Case management, support coordination and collaboration
• Collaboration - developing service integration through making and maintaining cross-agency relationships. What does a collaborative service system look like for people with disability? What needs to happen to avoid silo approaches?
• Support within the sector –professional opportunities, networking and knowledge exchange.
Problem solving together, workshops for disability and sexual assault services that focus on shared responsibility and models of support.

- Structuring ‘wraparound services’ and implement integration? Co-located services support integration and collaboration.

Communities of practice

- Building and extending communities of practice and professional networks across disciplines
- Building cross disciplinary communities of practice to counter silos of expertise

Authority of people with disability

- Peer mentoring and support; advice to workers – building authority in role for people with disability and what they say supports them
- Co-designed training, working with people with disability, to inform and train service providers across all sectors – modifying mainstream approaches

8.2 Summary of key priorities for improving access in services for children and young people with disability who have engaged in problematic and/or harmful sexual behaviours

8.2.1 Training delivery

Disability awareness

- What is disability? What are trauma responses? Diversity of disability, children and young people’s human rights and participation in society
- Recognising harmful sexual behaviours and using The Traffic Lights Tool, training for teachers, support workers, health, and disability support workers
- Trauma, intergenerational poverty and disadvantage, looking at the young person’s context and developing strategies for support

Disclosure

- Child first – young people who have engaged in problematic and/or harmful sexual behaviours are often victims of bullying or sexual violence. The child’s wellbeing is at the centre of intervention responses

Improving relational and cultural safety

- Flexibility – what does flexibility mean when working with young people in a person-centred way? How can clinical and social interventions properly address the needs of young people with diverse disability?
- Working with young people, working with their families, their networks and communities – young people in their context. How to manage and upskill young people’s networks to support positive behaviour change and social inclusion.
- Reflective practice – cultural safety and learning from communities; check ableist assumptions and remove systemic barriers to support marginalised young people. Healing Foundation’s Four pillars - safety, identity, reconnection and trauma awareness
- Working with families, recognising diversity and complexity of families, including supports for others with disability
- Respectful capacity building through rights-based approaches; New Street Model of practice – safety, restitution and wellbeing.
Practical skills

- Listening to children and young people with disability – addressing service gaps in knowledge and skills when communicating, child-centred methods with children with disability
- Disability, assessment and person-centred interventions. Drawing on strengths, recognising trauma, and solutions-based therapy models.
- Building on new skills, looking forward and maintaining safety - complexities and tensions for ongoing support as a person’s life changes and different challenges appear. Education for children and young people and their families, on sex and sexuality, respectful relationships
- Talking about sex - sex and sexuality education – for people across all sectors working with children and young people with developmental delay and limited language.
- Working effectively with children and young people with cognitive disability (children with intellectual disability, autism, acquired brain injury)
- What is safety? - online behaviours, social participation and talking about consent in a concrete way.

Building community capacity

- Looking to the future, developing knowledge and skills in the present - understanding violence and abuse, and healthy relationships education for:
  - Children and young people with disability included in mainstream sex and sexuality education, adapted resources,
  - Sex and sexuality education for people with disability
  - Disability and support workers
  - Families of people with disability
  - Networks of support

8.2.2 Resource development

Information about problematic and harmful sexual behaviour

- Clear information about how HSB services can respond to the needs of children and young people with disability

Information to support service use

- Easy to read, easy to understand, easy to discuss – communication tools for working with young people with disability that include non-verbal and pictorial resources (e.g. traffic lights tool)
- Adapting resources for clear communication between workers and young people. Guides and resources to facilitate difficult conversations in an appropriate and accessible way
- Online training resource – SECASA Dealing with Danger

8.2.3 Organisational support

Referral

- Young person’s complex needs, risk and ongoing support needs – where to go for help. Adopting the ‘no wrong door’ approach and referring across services to ensure children and young person have systems in place to improve the efficacy of interventions
Service integration

- Building relationships with families and with agencies to support the young person through case management, consistency and collaboration.
- Working with what is available, drawing on networks of support. Adapting available resources and networks to support the young person.
- Finding common ground – learning from each other. Working with person-centred approaches to promote interagency supports and cross sector collaboration education, health, child protection, and justice.
- Building networks with other organisations and participating in training and professional development.

Communities of practice

- Making networks, sharing information, making opportunities for resource and knowledge exchange including communities of practice.

**8.3 Summary of key priorities for improving access for co-design**

**8.3.1 Training delivery**

**Disability thinking**

- Learning from the experts – what does inclusion and participation mean for people with disability
- Understanding ability – working with strengths and respectful systems to ensure inclusive participation
- Understanding and respecting community protocols and listening across difference
- Speaking up, speaking back and listening – understanding and unpacking power dynamics, power structures and ableist assumptions

**Co-productive thinking**

- Reciprocal relationships - shared learning spaces and collaborative approaches to co-production
- Developing shared inclusive language

**Practical skill-building**

- Shared communication skills – working with communication aids, interpreters and translators, talking mats

**Leadership development**

- Developing inclusive and collaborative leadership skills- working with and developing capabilities

**8.3.2 Resource development**

- Communication aids, interpreters, talking mats, pictorial communication supports
- Unpacking key ideas in the project – developing a document to ensure shared meaning and shared language in the project
- Actively plan for resources to support people who may experience trauma through participation in co-design

**8.3.3 Organisational support**

- Rights based thinking - reciprocal relationships, working with diversity and learning from each other
9. Resources to support access to information for people with disability experiencing violence

Table 2 Resources to support access to information for people with disability experiencing violence

Note: A selection of resources from the most reliable and stable web sources have been provided here. We recommend that ECAV individually check reliability of links with the providers before recommending any resources in training.

<table>
<thead>
<tr>
<th>Program</th>
<th>Resource</th>
<th>Website</th>
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<tbody>
<tr>
<td>NDIS</td>
<td>Individual support and funding packages</td>
<td><a href="https://www.ndis.gov.au/">https://www.ndis.gov.au/</a></td>
</tr>
<tr>
<td></td>
<td>Information, Linkages and Capacity building – projects funded at community level to build inclusion</td>
<td></td>
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<tr>
<td>NSW Health</td>
<td>Specialised information on ‘care and management of care’ of child or adults with intellectual disability with complex health conditions that cannot be met by usual care. Skills training or other information sessions</td>
<td><a href="https://www.cesphn.org.au/documents/population-health/intellectual-disability/3246-sesldh-fact-sheets-intellectual-disability-health-teams-gp-teams/file">https://www.cesphn.org.au/documents/population-health/intellectual-disability/3246-sesldh-fact-sheets-intellectual-disability-health-teams-gp-teams/file</a></td>
</tr>
<tr>
<td>NSW Health (funded) Agency for Clinical Innovation Intellectual Disability Network</td>
<td>The Intellectual Disability Network is working to improve the care and health of people with intellectual disability across all ages by providing clinical leadership, research and education as essential elements to enhance the capacity of primary and secondary health services.</td>
<td><a href="https://www.aci.health.nsw.gov.au/networks/intellectual-disability/about">https://www.aci.health.nsw.gov.au/networks/intellectual-disability/about</a></td>
</tr>
<tr>
<td>Scope – making it happen (not for profit disability service provider)</td>
<td>Communication aids</td>
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<td></td>
<td>Rights aids</td>
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<tr>
<td>WWILD</td>
<td>Easy read resources –</td>
<td><a href="https://wwild.org.au/resources/">https://wwild.org.au/resources/</a></td>
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<td></td>
<td>WWILD women’s group</td>
<td><a href="https://wwild.org.au/groups/">https://wwild.org.au/groups/</a></td>
</tr>
<tr>
<td></td>
<td>Resources for families, professionals and communities</td>
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<tr>
<td></td>
<td>Training for support workers, professionals including online introduction to intellectual disability, responding to disclosure, and supporting recovery from trauma and other training as requested.</td>
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<tr>
<td>The Orange Door</td>
<td>Services for children, young people and adults, who have or are experiencing family violence, who need extra support with the care of children</td>
<td><a href="https://orangedoor.vic.gov.au/">https://orangedoor.vic.gov.au/</a></td>
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<tr>
<td>Program</td>
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<td>Website</td>
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<tr>
<td>Talking Mats</td>
<td>Specialist resource for supporting communication with people who have little language</td>
<td><a href="https://www.talkingmats.com/">https://www.talkingmats.com/</a></td>
</tr>
<tr>
<td>Women With Disabilities Australia</td>
<td>Range of research, issues papers on violence and women with disability</td>
<td><a href="http://wwda.org.au/">http://wwda.org.au/</a></td>
</tr>
<tr>
<td>Our Site</td>
<td>A website by women and girls with disability. Includes positive sexuality and relationships; safety and violence; leadership resources</td>
<td><a href="https://oursite.wwda.org.au/">https://oursite.wwda.org.au/</a></td>
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</tbody>
</table>
10. Consumer representatives, disability and sexual assault service providers, policy makers and academic stakeholder interview guide and feedback sheet

NSW Health Sexual Assault Services & Disability Access Project

GROUP INTERVIEW

Introduction

NSW Health with ECAV (Education Centre Against Violence) have commissioned research by UNSW and Flinders University. We are conducting a needs assessment of services for sexual assault for people with disability and children and young people with harmful sexual behaviours and their families, including those with disability. The study also supports ECAV to develop a co-designed evaluation framework of services.

In this group interview we want to find out and discuss

- What you know works, and what you think could be better
  - for sexual assault services for people with disability.
  - for services for children and young people with disability who have problematic or harmful sexual behaviours and their families.
- Your views of the brief summary of the literature. Are the findings consistent with what you know, and what is missing?
- Co-design and co-production – in your experience, how can services work with consumer groups and representatives effectively and respectfully?

We are particularly interested in your experience of programs that work. Much of the literature is focused on systems and while this determines how services function, we would like to know what practices or program models are useful or successful.

To inform ECAV’s practice, we want to know more specifically about what works in practice for people with disability.

- What are the programs and practices that work to support people with disability?
- What underpins the success?
- How do you measure the success?
- Response to findings (last two pages of this document) from the literature review. Do you agree or have any additional ideas that are missing here?

Brief summary overview from Needs Assessment literature review

Positive services for people with disability are those that respond to the intersectional nature of people’s lives and adopt wholistic approaches to any needs. Not all people with disability identify as living with disability and services need to be flexible, considering the person’s needs within the context of their lives and wider community.

Key factors in positive service systems for people with disability

- Capacity – resources, availability of services, workforce knowledge, skills and training
- Holistic service approaches – case management and working with the whole person, within their context, family and community, that includes supported decision-making and rights-based approaches services
- Accessibility – services are accessible, including staff attitudes, physical space, resources and information. Confidential, and culturally, emotionally and physically safe, and use supported decision making.

- Interagency or cross sector collaboration and communication (information sharing) for the benefit of the person needing services, for example education and health, that account for issues of confidentiality, cultural, physical and emotional safety.

- Education – relationships and sex education for children and young people, families and community, including practitioners in services. Community based prevention and education about sexual violence.

Sexual Assault Services for people with disability
Positive practice in pathways to services
1. Referral pathways are accessible, publicly known, easy to find and participate in, and are safe (confidential, culturally, emotionally and physically safe)
2. Information is accessible with multiple and adapted formats
3. Service pathways respond to the needs of the whole person

Barriers to pathways to sexual assault services
1. Recognition and understanding of sexual violence – for people with disability and for those working with them - conflation of victim survivor’s response to trauma associated with disability
2. Disclosure and risk - people with disability are discriminated against, and disclosure presents risk of further violence, leads to fear of losing independence and support networks, losing children, and not being taken seriously. Disability workers are mandatory reporters to their employers however, this does not necessarily lead to engagement with sexual assault services
3. Expectations and attitudes – workers’ and community attitudes toward people with disability and about disability and sexual violence.

Positive practices for sexual assault services
1. Services are relationship-based, and the victim survivor’s needs are at the centre of service responses.
2. Accessibility - information, attitude and physical accessibility, including communication supports and a care-coordinator. Confidential, and culturally, emotionally and physically safe, using supported decision making
3. Draw on expert knowledge from people especially women and girls with disability
4. Facilitates multisector collaboration and information sharing to accommodate person’s needs
5. Flexibility – in approach, service location and outreach (and capacity)
6. Workforce - staff have appropriate training, capacity (availability) and competency (and confidence). Workforce is diverse and skilled.
7. There are opportunities for peer and individual support programs.
Barriers to sexual assault services

1. Services do not accommodate the diverse capacities and needs of people with disability
2. Lack of data – comprehensive data collection can improve knowledge of victim survivor support needs, and service provision. Data is not being systematically collected to support this.
3. Services lack resources, and many have insecure funding.
4. Communication and collaboration across agencies are inconsistent.
5. Lack of worker education and training (for disability support workers about sexual violence and for sexual assault workers about disability needs and approaches, including supported decision making).
6. Community attitudes – to sexual violence and to people with disability
7. Policy gaps or conflicts – the National Plan to Reduce Violence Against Women and their Children employs a limited conceptual understanding of domestic/family violence that obscures the experiences of women and girls with disability and their accommodation settings. The National Disability Strategy includes limited attention to violence, gender and intersectionality.

Services for children and young people with disability who have problematic or harmful sexual behaviours, and their families

Promising practices in therapeutic models

1. Identification and recognition of problematic or harmful sexual behaviours by families and people working with children.
2. Strengths based, timely and proportionate in their responses. Programs are developmentally and culturally appropriate. Developing safety plans for children, who may themselves be at risk.
   - Wholistic, trauma informed responses that recognise children and young people often have other traumatic events in their lives.
3. Multi-modal approach to support children and their families, developing parent/guardian support and skills.
4. Multi agency partnerships and collaborations – a care coordinator to liaise across sectors and ensure consistency.
5. Workforce skills – education and training, trauma informed, for working with children and young people with disability

6. Barriers to effective services

1. Lack of evaluation of existing programs
2. Lack of appropriate relationship and sex education programs for children and young people with disability
3. Limited resources, time and availability of specialist services
4. Workforce – lack of capacity, confidence and training when working with children with disability. Limited staff in remote and rural areas for timely responses.
5. Lack of collaboration and partnerships between sectors
**NSW Health ECAV Disability Access Strategy – discussion feedback form**

This sheet was sent to all participants following interviews, and to any stakeholders invited who were unable to attend interviews.

Thank you for your contribution to our discussion about services for people with disability. This feedback sheet is to collect any other models or practice examples you know of, following our discussion.

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12. Glossary of terms and acronyms

CARC Royal Commission into Institutional Responses to Child Sexual Abuse
DRC Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
ECAV Education Centre Against Violence
Flinders Flinders University
NDIS National Disability Insurance Scheme
SECASA South Eastern Centre Against Sexual Assault
UNSW University of New South Wales
WWILD Working alongside people with intellectual and/or learning disability
WWDA Women with Disability Australia

Disability
The term ‘people with disability’ is used throughout this report to refer to a population group who are known to face barriers to equal inclusion to many services, including those that they need in times of crisis. People with disability are at least 20% of the population and are a highly diverse group – ranging from people who face few barriers to people who need support for every part of their lives.

Disability is understood as the intersection between a person’s impairment or health and their environment.  

Holistic approaches
Holistic approaches to care provision consider and accommodate the whole person, their physical, mental and psychosocial wellbeing, and respond to the individual and recognise intersectionality and the diversity of disability experience.

Intersectionality
Intersectionality theory helps in understanding how people live ‘on multiple axes of oppression simultaneously’, including, race, gender, disability, social identity and difference. The discrimination, disadvantage and exclusion that people face due to disability also connects to other dimensions of experience, such as being young, being part of lesbian, gay, bisexual, transgender or intersex communities, being from an Aboriginal or Torres Strait Islander or culturally and linguistically diverse background, and/or living in a regional, rural or remote community.

Person-centred support
Person-centred care is respectful of, and responsive to, the preferences, needs and values of the individual patient/person. Approaches in service delivery are focused on and driven by the person’s needs and wishes and not on service delivery capacity.

Problematic or Harmful Sexual Behaviour (PHSB)
The NSW Government Policy (2020) defines problematic and harmful sexual behaviours as

An umbrella term inclusive of the continuum of all concerning sexual behaviours that children may display. The term ‘problematic sexual behaviour’ has been broadly adopted to describe behaviour of a sexual nature outside the range accepted as ‘normal’ for a child’s age and level of development, is detrimental to development and normal functioning and places the child at risk of harm. The term

360 WHO https://www.who.int/health-topics/disability#tab=tab_1 accessed June 23, 2020
361 (Barrett & Pierre, 2011)
362 (Robinson, valentine, et al., 2020, p. 4; Shaw, Chan, & McMahon, 2012; Stubbs, 2015)
363 (Avery, 2018)
harmful sexual behaviour' is used to recognise that this behaviour may harm the child themselves, harm other children subjected to this behaviour, or place either child or children at risk of harm.365

Any behaviour of a sexual nature expressed by children under 18 years old that:
A. Is outside of what is culturally accepted as typical sexual development and expression
B. Is obsessive, coercive, aggressive, degrading, violent or causes harm to the child or others
C. Involves a substantial difference in age or developmental ability of participants366

Relationship-based support
The role and value of relationships is a fundamental aspect of support, and people are valued, respected and their rights recognised. Professionals develop rapport with clients, ensure trust and confidentiality.

Rights-based practice
Rights based practice in this context recognises people with disability and their right to equal treatment and equal opportunity, and non-discrimination with access to the full range of civil, political, economic, social and cultural rights.367 Rights-based approaches include participation, where people with disability have the right to participate in all decisions affecting them; accountability, services are accountable, monitored and compliant with human rights; are non-discriminatory and people who are marginalised and vulnerable are supported to access their rights.

Trauma-informed care
Trauma informed care is provided in a safe environment and supports the client and minimises the impact or trauma. It ‘employs actions, relational approaches and language that makes people feel safe, offers choice and is collaborative’.368

Violence, abuse and neglect
The NSW Government Policy (2020) defines violence, abuse and neglect:

an umbrella term for three types of interpersonal violence that are widespread in Australian communities: domestic and family violence; sexual assault; and all forms of child abuse and neglect. Children and young people with problematic or harmful sexual behaviour often present to NSW Health services.369

People with disability also experience violence, abuse and neglect in the following ways.

Violence and abuse: includes assault, sexual assault, constraints, restrictive practices (physical and chemical), forced treatments and interventions (including reproductive), humiliation and harassment, financial and economic abuse and significant violations of the privacy and dignity of people with disability on a systemic or individual basis.

Exploitation: is when a person takes advantage of someone else. This could include improper use of another person or withholding assets, labour, employment or resources including taking physical, sexual, financial or economic advantage of another person.

Neglect: includes physical or emotional neglect, passive neglect or wilful deprivation. A single significant incident or systemic; depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.

365 (NSW Government Relations 2020, p. 9)
366 (Meiksans et al., 2017, p. 3)
367 Women With Disability Australia have a range of resources and training that operates from a human rights based approach to support women and girls with disability http://wwda.org.au/about/ accessed June 18, 2020
368 (NSW Ministry of Health, 2019, p. 9)
369 (NSW Ministry of Health, 2019, p. 5)