Royal Commission Issues Paper: Health care for people with cognitive disability

Sexual Assault Support Service Inc. (SASS) Submission

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Sexual Assault Support Service

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Contents

Introduction

Sexual Assault Support Service (SASS) Inc. is a community-based service committed to providing high-quality support and information services to survivors of sexual assault in Southern Tasmania, carers and support people, professionals, and the general public. SASS offers a 24-hour sexual assault crisis response program; 24-hour phone support and counselling service to people affected by sexual assault; and face to face information, counselling, and referral services for anyone affected by sexual assault.

As part of our goal to provide responsive and holistic services to individuals, families, and the broader community, SASS facilitates therapeutic intervention services for children and young people (aged under 18 years) who are displaying harmful sexual behaviours.[1] This service is available free of charge for children aged up to 11 years, as part of our regular funding. For adolescents aged 12-17 years, we can provide behavioural change programs on a fee-for-service basis.

SASS is also funded to provide a Redress Scheme Support Service. This is a free and confidential support service for people who are seeking information on or wanting to apply to the National Redress Scheme.

SASS welcomes the opportunity to make a submission in response to the Royal Commission's Issues Paper.

[1] Alternative terminology is 'Problem Sexual Behaviour' (PSB) and 'Sexually Abusive Behaviour'(SAB).

1. Some statistics

SASS is aware that people with disabilities are at greater risk of experiencing violence than people without disabilities and are likely to face more barriers to accessing support services.[2] The most recent Personal Safety Survey (PSS) conducted by the Australian Bureau of Statistics (ABS) indicated that:

- 16% (935,000) of adults with a disability have experienced sexual violence after the age of 15, compared with 9.6% (or 1.2 million) without disability;
- 43% (2.5 million) have experienced physical violence, compared with 32% (4.1 million) without disability;
- 21% (1.2 million) have experienced intimate partner violence, compared with 13% (1.7 million) without disability.[3]

Evertsz and Miller (2012) explain that:

- fewer than 30 per cent of all sexual assaults on children are reported;
- children with intellectual disabilities are less likely to have the ability to report; and
- when abuse is reported, they are more likely to be ignored.[4]

General recommendation:

SASS's view is that family violence and sexual assault support organisations should be funded effectively to offer services that are flexible and responsive for all clients, including people of all ages with cognitive disability. Assured funding over time and dedicated resources for tailored supports and interventions would:

- help to maximise accessibility and equity;
- ensure that individuals and families receive the best possible support to meet their needs;
- enable organisations to invest in building staff capacity to work with people with cognitive disability; and
- enable organisations to develop and implement innovative approaches to service delivery.

[2] 1800 RESPECT (n.d). Web info: *Violence against people with disability*. Available at: https://www.1800respect.org.au/inclusive-practice/supporting-people-with-disability/

[3] ABS (2016) data, cited in Australian Institute of Health and Welfare (2019). Web report: *People with disability in Australia*. Available at: https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/personal-factors/prevalence-of-disability

[4] Evertsz, J & Miller, R (2012). *Children with problem sexual behaviours and their families*. *Best interests case practice model. Specialist practice resource.* Department of Human Services (VIC), p.18.

2. Harmful sexual behaviours – children and young people

A paper from the Commissioner for Children and Young People in Western Australia provides the following definition of harm sexual behaviours:

> Problematic or harmful sexual behaviours (HSB) can be defined as any behaviour of a sexual nature expressed by children under 18 years old that:
>
> - is outside of what is culturally accepted as typical sexual development and expression
> - is obsessive, coercive, aggressive, degrading, violent or causes harm to the child or others
> - involves a substantial difference in age or developmental ability of participants.[5]

Clinical data indicates that children with autism/Asperger's syndrome, ADD/ADHD, developmental delay and intellectual disability are overrepresented in groups of children displaying HSB.[6] Meiksans, Bromfield and Ey (2017) explain that children with intellectual disabilities are:

- more likely to suffer impulse control;
- less likely to be redirected by adults when displaying concerning behaviours;
- less likely to receive sex education; and
- at a greater risk of experiencing abuse and neglect, placing them at increased risk of trauma and sexualisation.[7]

Evertsz and Miller (2012) note that "[w]here a child experiences developmental delay or intellectual disability, additional resources, education or monitoring may benefit the child to prepare them for treatment."[8] They also emphasise that:

> It is important to be mindful that children with these behaviours are children first and foremost and that with appropriate treatment and targeted intervention, they have a good prospect of returning to a healthy developmental track. Every case has unique circumstances and must be responded to in the best interests of the child. While it is important not to minimise or ignore the problem sexual behaviours and to seek specialist advice and treatment, it is also important that the child is not defined by these behaviours and inappropriately labelled.[9]

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[5] Commissioner for Children and Young People (2018). *Discussion paper: Children and young people with harmful sexual behaviours*. Commissioner for Children and Young People WA, Perth, p.4.

[6] Pratt, R. (2013). A community treatment model for adolescents who sexually harm: Diverting youth from criminal justice to therapeutic responses. *International Journal of Behavioral Consultation and Therapy*. Number 8, Issues 3-4, p.41; and O'Brien, W. (2010). *Australia's Response to Sexualised or Sexually Abusive Behaviours in Children and Young People*. Australian Crime Commission, Canberra, p.14.

[7] Meiksans, J., Bromfield, L., & Ey, L. (2017*). A Continuum of Responses for Harmful Sexual Behaviours. An Issues Paper for Commissioner for Children and Young People Western Australia.* Australian Centre for Child Protection, p.6.

[8] Evertsz, J. and Miller, R. (2012). *Children with problem sexual behaviours and their families. Best interests case practice model. Specialist practice resource*. Department of Human Services (VIC), p.39.

[9] Ibid, p.7.

General recommendations:

Government funding bodies across Australia:

- acknowledge the increase in demand for specialised programs that focus on harmful sexual behaviours; and
- provide ongoing funding that enables organisations to (a) meet this demand, and (b) deliver tailored interventions for children and young people with complex communication needs and/or cognitive disabilities.

3. SASS's approach to service delivery

SASS is committed to the delivery of trauma-informed support services. Trauma-informed practice provides a framework for working with people of all ages and backgrounds. Wall, Higgins and Hunter provider the following explanation of what trauma-informed care means:

> Trauma-informed care could be described as a framework for human service delivery that is based on knowledge and understanding of how trauma affects people's lives and their service needs (Harris & Fallot, 2001). This requires consideration of a person's environment beyond the immediate service being provided and of how their symptoms and presentations may be seen as adaptations to trauma rather than as pathologies (Herman, 1992). At the broadest level, trauma-informed care means that services have an awareness and sensitivity to the way in which clients' presentation and service needs can be understood in the context of their trauma history (Knight, 2015). Kezelman and Stavropoulos (2012) noted that trauma-informed health and welfare settings and systems contrast dramatically with traditional settings and systems as they require different ways of operating, and without this understanding, risk re-traumatising service users. Trauma-informed approaches to care could be described as a strengths-based framework that is responsive to the effects of trauma (Bateman et al., 2013).[10]

SASS's practitioners gather relevant information about all new clients and their support needs, in accordance with what the client is comfortable to share. Disability is not a barrier to accessing our counselling and support services; furthermore, SASS recognises that some clients choose not to describe themselves as having a disability, even if they access the National Insurance Scheme (NDIS) or receive a Disability Support Payment.[11] SASS's practitioners provide an overview of trauma-informed practice; find out if there are particular counselling methods or activities that have worked well in the past; and where necessary,

[10] Wall, L., Higgins, D., & Hunter, C. (2016). *Trauma-informed care in child/family welfare services*. Australian Institute of Family Studies, CFCA Paper No.37. Available at: https://aifs.gov.au/cfca/sites/default/files/publication-documents/cfca37-trauma-informed-practice.pdf

[11] Tip sheet: Working with women with disabilities. Domestic Violence Resource Centre Victoria and Women with Disabilities Victoria. Available at: https://www.dvrcv.org.au/sites/default/files/Advocate_201808_p15_Working%20with%20women%20with%20disabilities%202.pdf

discuss how we might adapt our approach to meet the client's support needs. Sometimes, SASS and the client (or the parent/guardian, where the client is a child or young person) will agree to begin counselling or a therapeutic intervention and see how things go. Part of our trauma-informed approach to counselling and support with all clients is checking in regularly about what activities and interventions are working well, and if any changes need to be made.

4. Levels of demand for SASS services

Over the past decade, SASS has experienced ever-increasing levels of demand for our services, including behavioural interventions and supports for children and young people who are displaying harmful sexual behaviours. In 2017/2018, we received State Government funding to deliver a pilot program for young people aged 12-17 years. This was a successful program, and we hope to be able to deliver it again in future.[12] However, it was clear over the course of this program that dedicated funds were needed for staff training in working with clients who have complex communication needs and/or a cognitive disability. Data gathered from this pilot revealed that approximately half of all children and young people participating in the pilot program had an intellectual or learning disability. Whilst these figures cannot be considered statistically significant due to the small size of the group, they do indicate a need within this particular cohort.

We are aware that other organisations experience resource-related challenges in providing tailored sexual trauma counselling and supports, and/or harmful sexual behaviour intervention programs, for people who have cognitive disabilities and/or complex communication needs.[13] Relatively small, non-government organisations like SASS tend to have limited budgets for professional development. We strive to do the best we can with what we have but this not ideal, in terms of responding effectively to individuals and families who present with complex needs. This is discussed further in the next section.

5. Barriers and challenges

Resources and training

SASS receives referrals where it is clear that the client requires support or an intervention from someone who has training and experience in working with people who have complex communication needs and/or cognitive disability. Sometimes, parents/guardians enquire

[12] We now offer a limited service to this cohort, on a fee-for-service basis.

[13] For example, see:

Commissioner for Children and Young People (2018). *Western Australian service mapping – Services for children and young people who have experienced sexual abuse or display harmful sexual behaviours*. Commissioner for Children and Young People WA, Perth.

Jenkins, D. (2018). *The Victorian Centres Against Sexual Assault: Responding to Victim/Survivors with Intellectual Disability or Complex Communication Needs.* Available at: https://www.casa.org.au/assets/Documents/Responding-to-Victim-Survivors-with-Intellectual-Disability-or-Complex-Communication-Needs.pdf

whether we have counsellors who are specially trained in working with children who have autism and complex communication needs (for example). Our capacity to accept these referrals depends on the severity of the child's disability. Where a child has a moderate to severe disability we are usually unable to take on the referral as we do not have the specific skill set required. Where possible, we assist the client/family with a referral elsewhere. Depending on presenting needs and concerns, we may refer children, young people and their families to Family Planning Tasmania's Additional Needs Program (see Program overview at Appendix A). However, we are aware that other organisations and individual practitioners to whom we might refer are not necessarily specialists in sexual assault support and trauma-informed practice.

In the research paper titled 'The Victorian Centres Against Sexual Assault: Responding to Victim/Survivors with Intellectual Disability or Complex Communication Needs', Jenkins (2018) recommended:

> (1) That counsellor/advocates with experience working with victim/survivors with [complex communication needs] and [intellectual disability] mentor and support other workers; this may involve funding a worker at each CASA (as per recommendations from the Evaluation of the Making Rights Reality project (Frawley, 2014)) to serve as a source of secondary consultation and dissemination of information and resources.[14]

SASS supports this recommendation. If SASS were to receive funding for such a position, the role would include the delivery of training activities on relevant topics (e.g. use of communication tools and assistive technology for work with people who have complex communication needs), for SASS staff and other organisations if requested. Training and mentoring would be informed by research and the work of innovative programs and models in Australia and overseas. The role would also involve providing information and guidance to the broader community, by offering primary prevention activities and consulting with other agencies for the benefit of people with disabilities and their families.

We submit that at a minimum, organisations like SASS must have the funding to train staff in working with people with complex communication needs and/or cognitive disability. This training could be made available to multiple organisations, and there could be online components to reduce costs associated with full face-to-face delivery.

Family members as interpreters

Where possible, SASS avoids the use of family members and other support persons as interpreters. Confidentiality is a primary concern, where the client is a young person or an

[14] Jenkins, D. (2018). *The Victorian Centres Against Sexual Assault: Responding to Victim/Survivors with Intellectual Disability or Complex Communication Needs.* Available at: https://www.casa.org.au/assets/Documents/Responding-to-Victim-Survivors-with-Intellectual-Disability-or-Complex-Communication-Needs.pdf

adult.[15] In the CASA Forum paper mentioned above, Jenkins (2018) includes a relevant quote from a survey participant as follows:

> Once a parent needed to be present to "translate" for the client. I feel this compromised the client's confidentiality in sessions, and may have limited the issues she raised. On the other hand, I would not have been able to understand this client much at all without her parent being present to help me understand her.[16]

In addition to our concern about respecting the client's right to confidentiality, we are aware of inadvertent risks and outcomes, such as sessions becoming focused on the priorities of the family member rather than the client. A serious risk to consider is the possibility that the family member who is acting as interpreter may be engaging in abusive behaviour (e.g. physical, sexual, emotional, and/or financial) towards the client, or has done so in the past. Having staff who are trained in working with people with complex communication needs would reduce the need to rely on others for interpreting assistance.

NDIS Accreditation

In 2019, SASS explored the option of pursuing NDIS Accreditation. NDIS Accreditation would enable SASS to work collaboratively with other NDIS-funded organisations and practitioners, for the benefit of individuals and families. However, we found NDIS accreditation to be prohibitively expensive. For more than 10 years, SASS has maintained Quality Improvement Council (QIC) accreditation, and we were hopeful that this would be recognised for NDIS Accreditation purposes – even on a partial basis. We were advised that our existing accreditation could not be considered. Finding the resources for two separate accreditation processes was not realistic, so the option was not explored further.

Specific recommendations:

- At a minimum, sexual assault support services are resourced to provide their counselling staff with access to comprehensive training in working with people with complex communication needs and/or cognitive disabilities.
- Ideally, sexual assault support services are resourced to have at least one (1) practitioner role that is focused on the provision of therapeutic supports for people with complex communication needs and/or cognitive disabilities (and their families, where relevant), plus the provision of mentoring and training for other staff and the wider community.
- Costs and processes associated with NDIS Accreditation are reviewed and modified, to ensure that Accreditation is accessible to relatively small, non-government organisations.

[15] Where the primary client is a child, SASS does engage with the parent or guardian throughout the counselling/support process.
[16] Jenkins, D. (2018). See reference info at Footnote 14 above.

Appendix A

Family Planning Tasmania provides specialist relationships, sexuality and sexual health education for children and adults living with:

- physical, intellectual or developmental disability
- acquired brain injury
- Autism Spectrum Disorder
- trauma or other needs that impact on learning.

Education sessions can be provided for either individuals or small groups and topics include:

- private body parts
- being private
- puberty and adolescence
- managing periods
- types of touch
- relationships
- sexual health and STIs
- contraception
- protective behaviours for social and sexual safety
- giving and receiving consent
- sexual abuse issues
- sexual feelings and masturbation
- strategies for social and sexual behaviours

As part of the support we provide through our education sessions for people with additional needs, we also work with:

- family members
- support workers
- teachers and teacher assistants
- any other person who provides support for the person with additional needs.[17]

[17] From Relationships and Sexuality Additional Needs Program flier, available at: http://www.fpt.asn.au/wp-content/uploads/2018/11/Additional-Needs-Program.pdf