Avoiding and responding to sexualised behaviours of concern in young people with intellectual disability and autism spectrum disorder

A guide for disability service providers

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The image used on the cover of this publication is ‘People’, a painting by Brady Freeman, one of the winners of the VALID art competition, sponsored by the Senior Practitioner and presented at the VALID annual Having a Say Conference 2016

# Purpose of this practice guide

This guide is designed to provide direction to disability service providers in their support of young people with intellectual disability and autism spectrum disorder who show sexualised behaviours of concern (SBoC). The guide takes a deliberate positive approach to supporting the development of sexuality of young people with these disabilities and uses the published evidence to outline standards for the assessment of, and intervention for, sexualised behaviours of concern. This guide was developed primarily for disability service providers, however its application to other sectors including schools and family homes and use by clinical professionals is also appropriate. The recommendations are presented in the context of positive behaviour support (PBS) in order to maximise their practical value in improving the quality of life of young people with SBoC and in reducing SBoC[[1]](#endnote-2).

# Introduction

Children and young people with disabilities who show sexual behaviour are often viewed as a concern if these behaviours are socially inappropriate or considered to be harmful to the young person or others. Such behaviours may be illegal or likely to interfere with significant aspects of life such as school or service access. The parents of children with intellectual disability (ID) and autism spectrum disorders (ASD) who engage in SBoC are primarily concerned with the child’s safety and others’ understanding of their children’s behaviour[[2]](#endnote-3).

Children and young people with autism spectrum disorders (ASD) have impairments in three main domains comprising communication, restricted behaviour and interests, and social interaction[[3]](#endnote-4) and it is these particular impairments which may impact sexual development and contribute to SBoC[[4]](#endnote-5). In addition, impairments associated with intellectual disability (ID) such as cognitive functioning and difficulties with tasks of everyday living, referred to as adaptive functioning3, is present in up to 70 per cent of those with ASD[[5]](#endnote-6). Considering this, we can begin to understand the factors which may contribute to SBoC in this group.

# What do we already know?

## Sexual development

Persons with ASD are sexual beings who display a wide range of sexual behaviours[[6]](#endnote-7) which requires sexual education; however the sexuality education for individuals with autism is an emotional issue[[7]](#endnote-8). The limited understanding of the sexual expression of individuals with ASD and ID may mistakenly cause such behaviours to be considered abnormal or potentially dangerous4.

Masturbation is the most commonly reported sexual expression for people with ASD6 and it is a normal part of sexual developmentt[[8]](#endnote-9). Therefore it is necessary to acknowledge that masturbation may be the only outlet for sexual expression for this group7. In adults with autism and intellectual disability, no relationship has been found between irritability, agitation and aggressive behaviour and masturbation, which is different to caregivers’ opinions that individuals who are not getting their sexual needs met are likely to be more irritable and more aggressive[[9]](#endnote-10).

Adolescence is a developmental stage for all young people with disabilities[[10]](#endnote-11) where sexual experimentation and exploration are a normal part of adolescence and young adulthood[[11]](#endnote-12),8. Families have referred to the experience of youth with ASD entering adolescence as the ‘second crisis’2 as this period is a time of reorganisation of biological, emotional and social functioning[[12]](#endnote-13). A complex relationship exists between hormone levels and behaviours such as adjustment, emotional temperament and aggression and combined with this is a period of risk-taking which is encouraged by development of the brain’s reward/aversive systems[[13]](#endnote-14). These biological factors of adolescent development indicate that some difficult behaviour is expected during this time and cannot be eliminated.

## Behavioural problems during adolescence

Increased behavioural problems during adolescence in those with ASD, especially those also with ID, have been recognised[[14]](#endnote-15),[[15]](#endnote-16),[[16]](#endnote-17),[[17]](#endnote-18),[[18]](#endnote-19),[[19]](#endnote-20),[[20]](#endnote-21). Individuals with autism typically mature physically and sexually according to normal developmental stages, however a young person with disabilities can develop normally in some areas but have difficulties in social understanding7 while the emotional changes and increasing sexual urges may be delayed or prolonged[[21]](#endnote-22). The impulsiveness, aggressiveness and defiance occurring in adolescents with autism are not so different from the same behaviours seen in normal adolescent development[[22]](#endnote-23),[[23]](#endnote-24).

## Understanding sexualised behaviours of concern

There is no one shared definition or understanding of what constitutes SBoC[[24]](#endnote-25),[[25]](#endnote-26). SBoC may include several behaviours such as making obscene gestures, touching private body parts of another person, non-consensual hugging, exposing one’s own body parts, disrobing and masturbating publically[[26]](#endnote-27), touching own private body parts in public, discussing inappropriate sexual subjects, looking up skirts or down shirts4 and non-consensual touching of non-genital parts of the body25. This suggests potential confusion may develop when considering if behaviour is sexually inappropriate.

## Behaviour may not be sexual at all

It is necessary to consider that SBoC may not be sexually motivated and may be better accounted for as:

* a stereotyped and repetitive behaviour in ASD9
* the relief of boredom[[27]](#endnote-28),[[28]](#endnote-29),[[29]](#endnote-30)
* a lack of opportunity for privacy may inadvertently result in behaviours being displayed in public areas7,26,28
* behaviours may be an expression of a desire for intimacy in someone who cannot adequately express it26
* ill-fitting clothing and physical health problems such as tight foreskin and urinary tract infection28 may result in touching and interfering with clothing which is misinterpreted as SBoC.
  + a functional behaviour for the person in achieving something irrespective of whether an observer could identify it or not.

SBoC may not be responsive to social disapproval[[30]](#endnote-31),[[31]](#endnote-32) and because a behaviour feels good, what others think about it takes a secondary position30,28.

More practically, medications may affect libido, arousal and ejaculation[[32]](#endnote-33),7,26,30,29 so, for example, a young man experiencing erection difficulty may masturbate frequently in the hope of achieving a better erection[[33]](#endnote-34). The immediate feelings from self-stimulation and masturbation are strong reinforcers to behaviour in all settings, including in public[[34]](#endnote-35), however SBoC may also have an attention, escape and/or tangible function[[35]](#endnote-36).

# Assessing sexualised behaviours of concern

The following factors are relevant considerations when undertaking an assessment and designing an intervention for SBoC (developed from11,[[36]](#endnote-37)):

|  |  |
| --- | --- |
| Family | **The structure of family relationships**  What are the family’s beliefs and practices regarding nudity, sexuality, masturbation, intercourse and gender? |
| **Family of origin factors**  If the young person is not in the care of their biological family, were there any sexual factors related to their placement? |
| **Care history**  Frequent changes in residence and support are destabilising and increase risk of abuse. Has the young person been abused? |
| Individual skills | **Adaptive functioning versus chronological age**  Young people with disabilities have skills which may not be as developed as their peers of the same age. Take care when comparing behaviour between children and refer to specific assessment of the child’s abilities. |
| **Developmental history**  What were the young person’s learning and behavioural characteristics as a child? What kind of skills did they quickly develop and what was more difficult? |
| **General intellectual functioning**  This is obtained from an IQ assessment administered by a psychologist to identify cognitive strengths and weaknesses across a broad set of skills. This must not be the sole area of assessment in SBoC. |
| **Degree of self-regulation**  How successfully can the young person independently terminate preferred and initiate non-preferred tasks and activities? |
| **Social functioning, interest and rejection**  How do the young person’s social and communication skills promote or inhibit interaction with others? |
| Health | **Physical maturation and sexual development**  Physical sexual characteristics are associated with hormonal changes which in turn influence behaviour. Is sexual behaviour consistent with sexual development? |
| **Personal health history**  Are there any physical health conditions which may mimic sexual behaviour? Some prescribed and over-the-counter medications can have unintended side effects such as behavioural disinhibition and may affect libido, arousal, ejaculation and menstruation. Is there irritation to the genitalia or anus? |
| **Psychosexual development**  Does the young person have the opportunity to seek and maintain intimate relationships, manage complex emotions, achieve independence in self-care tasks? How may clothing, equipment and dependence affect self-esteem? |
| Sexual knowledge | **Base knowledge of socio-sexual information and rules**  Does the young person have knowledge of different types of relationships (i.e. family, friends, intimate), different types of physical contact, consent, and the confidence and ability to seek help and report unwanted sexual attention or abuse? |
| **Educational history**  Does the young person have words to describe body parts and sexual behaviours? Does the young person understand personal care and hygiene needs? (Refer to the section about education elsewhere in this guide.) |
| Sexual behaviour | **Experiences and opportunities for normal experimentation with age-appropriate peers**  It is normal and expected that young people experiment in regards to their emerging sexuality and this requires social opportunities to do so. Does the young person have this opportunity? |
| **History and meaning of problematic sexual behaviour**  Has this or a similar or related behaviour occurred at another time? What intervention was undertaken at that time and was it successful in addressing the behaviour? |
| **The young person’s response to discovery and intervention**  Did the young person show embarrassment or remorse or any other emotional response which demonstrates acknowledgement of social expectations? Did their subsequent behaviour change? |
| Response to sexual behaviour | **The parents’/carers’ response to disclosure**  Was the response from the young person’s parents or carers reasonable in the circumstances? Do they demonstrate knowledge of appropriate sexual behaviour based on the child’s development and abilities? |
| **Involvement of clinicians and the legal system**  Has the young person previously received specialist clinical services related to their SBoC? What were the recommendations from this service for future SBoC? Has the young person ever had formal contact with the justice or legal system related to SBoC? Does the behaviour require mandatory reporting to authorities and/or reporting required by policy? |

This approach is consistent with the assessment practices of Positive Behaviour Support (PBS)[[37]](#endnote-38) which focus on contextual variables over protracted periods of time. Contextual variables are those events most likely to have a functional relationship to the SBoC and which should be further assessed through functional behaviour assessment (FBA). These contextual variables can include[[38]](#endnote-39):

* Negative interactions (e.g. disagreement, communication, unfamiliarity)
* Disappointments (e.g. activities cancelled, wishes not met)
* Tasks/activities (e.g. new, difficult, no choice)
* Daily routines (e.g. boredom, inability to leave, transitions)
* Uncomfortable environment (e.g. noise, temperature, seating)
* Changes in environment (e.g. lost items, unfamiliarity)
* Medication (e.g. changes, side effects)
* Illness (e.g. acute and long-term)
  + Psychological states (e.g. hunger, thirst, fatigue, menstruation).

Accurate identification of contextual variables can be used to design interventions that prevent SBoC from occurring, however it does not provide information about why a particular variable is associated with the behaviour. In order to understand why an SBoC is occurring, functional behaviour assessment (FBA) is required. FBA has been specifically recommended for investigating SBoC11,[[39]](#endnote-40),[[40]](#endnote-41),25,33,30,26,[[41]](#endnote-42) and is a core feature of positive behaviour support[[42]](#endnote-43).

## Functional behaviour assessment

FBA is the process of collecting and analysing data about behaviour in the format of antecedent-behaviour-consequent (ABC), or setting-trigger-action-response (STAR):

| Setting event  (Setting) | Antecedent  (Trigger) | Behaviour  (Action) | Consequence  (Response) |
| --- | --- | --- | --- |
| A variable that influences the display of a behaviour, i.e. what made the behaviour more likely to have occurred? (see discussion above) | What triggers the behaviour, who was there, what was about to happen, what was said, what occurred immediately before the behaviour? | Towards whom or what is behaviour directed?  What did the behaviour look like?  What were the specific observable details about the behaviour? | Describe how others reacted to the behaviour. What happened immediately following the behaviour, what was done, what was said, how did others react? |

The details of FBA are important in making a distinction between the processes of identifying what behaviours are occurring and identifying why they are occurring[[43]](#endnote-44). Refer to resources from the Office of Professional Practice and other reliable sources of information online regarding how to conduct FBA.

Even if the behaviours related to achieving sexual enjoyment have not been learnt, enjoyment may reinforce the behaviour[[44]](#endnote-45). This necessitates the provision of supportive policies for sexual expression in services which support people with all disabilities in order to proactively address appropriate sexual behaviour. Government funded human services have policies and procedures for supporting safe sexual behaviour and these must be supported by local organisational policy and procedures.

Assessment of SBoC requires attention to both the personal factors of the person and the components of the behaviour in order to comprehensively understand the challenges faced by the person and adequately plan intervention.

# Intervention for sexual behaviours of concern

A number of basic principles have been identified for behaviour intervention in SBoC, including:

* the different types and degrees of assistance which may be required by the person23
* not using punishment but rather encouraging appropriate behaviour7,35
* not only approving or allowing heterosexual behaviour[[45]](#endnote-46)
* as skills are learnt, supervision is reduced[[46]](#endnote-47)
* intervention must be consistent with strategies already successfully implemented for the young person11,22
  + replacement of inappropriate behaviour with a functionally equivalent appropriate behaviour.

Replacing a sexual behaviour with a non-sexual behaviour may be unsuccessful as another behaviour is unlikely to be preferred over sexual enjoyment or orgasm[[47]](#endnote-48). This consideration supports the positive approach to behaviour support for behaviours of concern, including SBoC, and is consistent with the person-centred planning and self-determination values of PBS.

Multidimensional approaches to intervention are recommended28,46 which may involve one or more of: decreasing inappropriate behaviour, increasing appropriate behaviour, increasing social skills and teaching self-management skills.

In contrast to this, redirection to another activity is often suggested, however redirection to a place with adequate privacy such as a bedroom or bathroom, and provision of scheduled breaks or private leisure time so the person can anticipate times for personal needs such as masturbation7, is more fitting with a positive approach.

## Guidelines for responding to SBoC

Guidelines for responding to SBoC in persons with cognitive disabilities have been proposed which are also applicable to persons with ASD and ID28:

1. Do not perpetuate a status of perpetual minors. People with disabilities, just like those without, have responsibilities when living in the community, which includes compliance with laws and norms regarding social behaviour. People with disabilities require education and support from staff, carers and parents which teaches and reinforces appropriate social behaviour.
2. Do not anticipate or overreact to, sexualised behaviours of concerns around puberty. Puberty is a time of confronting physical and emotional development for all young people, including those with disabilities. Sexual behaviour at this time may be more overt, especially if a young person does not have the skills to self-regulate their behaviour.
3. Aim for self-regulation and differentiation in controlling SBoC. Every young person should be given the permission, knowledge and skills to engage in solo, safe sexual behaviour when they desire at appropriate times. To ensure that the support of young people regarding sexual behaviour is sustainable and models acceptable standards, young people should be taught to initiate appropriate sexual behaviour themselves rather than rely upon an adult to prompt them.
4. Avoid non-consented, intrusive interventions. A variety of laws stipulate that everyone has rights, and people with disabilities are afforded special rights due to their vulnerability. Any intervention in response to SBoC should not unnecessarily limit a young person’s rights. For example, this includes freedom of movement, privacy, and not being subject to unnecessary or unproven medical treatment or treatment which inappropriately places them at risk of adverse effects. The Disability Act 2006 and the Charter of Human Rights and Responsibilities Act 2006 provide guidance for considering these and other human rights.

A framework for sexual behaviour intervention which is relevant to people with ID and ASD has also been proposed33:

1. Choose one behaviour in most need of change based on the extent to which the behaviour impinges on others and the extent to which it poses a risk to the person themselves.
2. Involve the person as much as possible in changing the behaviour through giving them choices, scheduling their preferred activities, giving them time alone with privacy and generally providing them with a fulfilling and engaging life.
3. Find alternatives and reinforcers that will help the person change the behaviour through safe and fulfilling sexual exploration and provide meaningful reinforcement for appropriate behaviours.
4. Maintain a consistent approach to support and intervention of the young person across all settings, for example school, respite and home. This ensures that skills can be practised regularly and behavioural expectations are known and can be reinforced. This is best achieved through the use of a behaviour support plan.
5. Ensure that the message about the behaviour is clearly communicated, both verbally and nonverbally, as young people with ASD and ID have difficulties with communication, both understanding what they hear and expressing what they know or want.
6. Remember that only the person’s behaviour is being assessed as inappropriate, not them personally. Derogatory terms or labels must not be used when describing the young person, nor should medical diagnoses be used to describe a person’s behaviour.

These guidelines are, overall, consistent with PBS insofar as taking a broader approach to SBoC intervention which addresses the broader support needs of the individual to enhance their quality of life.

## Caution with sexuality and human relations education

Sexuality and human relations programs designed for individuals with ID do not necessarily address the social impairments characteristic of ASD[[48]](#endnote-49),[[49]](#endnote-50),22,21,34,41,[[50]](#endnote-51). Many education programs for people with ID have generally been unevaluated[[51]](#endnote-52),[[52]](#endnote-53) and there is little research to demonstrate that persons with ID generalise knowledge or skills to their daily lives48. Few programs are specifically designed for young people with ASD41 and the ones that do exist typically focus on the more able end of the autistic spectrum and are in a format which is difficult for the learner. They also focus on social skills, which is not the primary need of this group34. Young people with ID and ASD require very clear knowledge about what sexual behaviour they can do and where they can do it.

The following points should be considered prior to engaging an educational program for SBoC[[53]](#endnote-54):

1. Describe the SBoC objectively and do not pre-determine the cause (e.g. lack of knowledge) at the time of referral
2. What are the expected outcomes of the intervention and how will they be measured?
3. What is the scientific basis of the intervention?
4. How has the intervention been evaluated in order to know that it works?

The young person’s skills must be assessed before, during and after intervention48,49 in order to establish what they need to learn and evaluate if they have in fact learnt what they were taught.

Four developmental levels for the provision of sexuality and human relations education to individuals with autism have been recommended23. The usefulness of the levels is that the needs of those with ID are considered and explanations for aiming for more basic skills are provided.

* **Level 1:** discriminative learning: knowing when and where to disrobe, masturbate, touch other people, and related behaviours
* **Level 2:** personal hygiene: cleaning themselves properly after a bowel movement, appropriate hygiene during their menstrual periods, changing underwear, cleaning themselves appropriately in a bath or shower, using deodorant, and related behaviours
* **Level 3:** body parts and functions: introduce concepts of body parts and their functions and be sure these are understood
  + **Level 4:** a comprehensive sexuality and human relations education program

These levels match the skills of a person, and as they achieve all of the skills related to a specific level, they are ready to move onto higher skills.

Providing education to a young person after they have engaged in SBoC is unlikely to be successful23 because the relationship of their sexual behaviour to the consequence of the behaviour is not immediate and it is too difficult for the young person to make the association between their behaviour and what they have learnt in an unrelated scenario. Simply providing ‘education’ should never be the sole intervention, as a true educative response includes opportunities to practice learnt skills in everyday life, with support from adults. In addition, responding to behaviours too long after they have occurred risks being draconian and discriminatory because there is no opportunity for assessment-based intervention[[54]](#endnote-55). A holistic approach to supporting the sexuality needs of young people with ID and ASD through proactive education is necessary to avoid the development of inappropriate behaviour - the second aim of positive behaviour support37.

# Responsibilities of service providers

Providers of services to young people with ID and ASD have a requirement to support young people effectively, however the ‘how and when’ aspects of staff intervention for SBoC are often made worse by:

* low confidence of staff in intervening[[55]](#endnote-56)
* arguments about whose responsibility it ultimately is to provide such an intervention2,[[56]](#endnote-57),[[57]](#endnote-58)
  + confusion about who is responsible for evaluation of the interventions35

These points have all been identified as integral considerations in an organisation’s response to SBoC and are important components in a PBS approach to service delivery.

The learning of appropriate sexual behaviour should occur in regards to the rules and norms of where the person lives7. Environments which support multiple people (such as respite or group homes) or those which are restrictive may discourage the use of other means of supporting safe sexual expression. This requires service providers to have policies that support a person’s sexual expression29 as it is acceptable for a person to express their sexuality within the confines of their social contacts7, which, in the case of young people with disabilities, may be limited to school, respite or other support services.

It is difficult for organisations to identify when SBoC becomes a ‘problem’, and further difficulties are encountered when there is no confirmed evidence that SBoC had occurred yet a young person is believed to have engaged in SBoC which poses a risk of harm to others54. Together and separately, these issues point to the need for organisations to have clearly established policy and procedures for responding to SBoC,. The risk of maintaining an informal approach to SBoC is that young people may be subject to random interventions which are “not based on any clear rationale or monitored against clear criteria, to which they have not consented and for which there are no accessible complaints or review procedures”54 p. 194.

Ten recommendations for service providers when supporting young people with intellectual disability and ASD who display sexualised behaviours of concern have been identified[[58]](#endnote-59):

|  |  |
| --- | --- |
| Avoid simplistic explanations for SBoC | This includes the use of pejorative or medical terms in an attempt to explain behaviour, or of behavioural terms without first undertaking FBA. Consider:  how the impairments of ASD affect the individual person  poor engagement in meaningful activity  lack of privacy and intimacy  clothing and physical health concerns  lack of pleasure, excitement and gratification. |
| Clear policy and procedure for responding to SBoC | Organisations have unambiguous policies and procedures which direct staff actions in situations where SBoC has occurred and which protect the rights of all parties, including the young person who has engaged in the behaviour. Consider:  support for sexual expression  a clear threshold for when sexual behaviour becomes problematic or inappropriate  interventions are evidence-based and implemented in a transparent manner  educative interventions are not provided in isolation and not offered only following a crisis. |
| Staff education and training | Any education or training provided to staff addresses staff’s attitudes and values and subsequent changes in their practice following education or training can be evaluated. Consider:  potential bias towards evidence of sexual expression in males  knowledge and skills in when and how to intervene  acknowledgement of staff responsibility to intervene. |
| Accurate use of functional behaviour assessment (FBA) | Functional behaviour assessment is utilised to identify the setting, events, antecedents, consequences and function of the behaviour. Consider:  methods of data collection  accurate recording of objective data  adequate and regular analysis of data  data informs the development and revision of a support and intervention plan. |
| Interventions go beyond addressing the specific behaviour to consider support for wider aspects of the person’s life | Consistent with PBS, the young person’s entire life is considered to ensure that they are supported to have rich and fulfilling experiences which provide many opportunities for enjoyment and gratification. Consider:  utilisation of a wraparound approach  increase social competence and communication skills  physical health conditions are identified early and treated as necessary. |
| Leadership and motivation of staff | Effective leadership is necessary to provide support and practical guidance to staff in their day-to-day work with young people, especially when SBoC occurs. Leadership ensures compliance with accepted standards of practice and encourages staff to persist when faced with adversity. Consider:  value statements for the sexuality of people with disabilities  frequent and effective staff supervision  frequent and useful team meetings  on-the-job training  coaching in the workplace. |
| Resources are made available to enrich the material and social environment | Barren, unengaging and unwelcoming environments perpetuate behaviours of concern and negatively affect staff morale and performance. Resources are necessary to provide interesting, inclusive and challenging opportunities for young people which build on existing skills and provide prospects for staff to engage the young person in meaningful activity. Consider:  social contact  purposeful and meaningful activity  sufficient staffing at necessary times  provision of sensual and relaxing experiences which are not sexualised. |
| There is capacity within the organisation for complex decision-making and risk management | Capacity refers to management and practice staff who have the necessary knowledge and skills to make informed decisions when responding to SBoC. These decisions do not negatively impact the young person or staff and also make significant contributions to the resolution of the SBoC. Consider:  addressing behaviours in a formal and evolved manner  formal recording in case notes  the reputation of individuals involved  ability to justify concerns and management strategies  behaviour support plans are in place and are revised regularly  maintaining choice, least restrictiveness and confidentiality. |
| Professional support is available to the staff group as required | When there is an insufficient response of the young person to assessment-based intervention, the organisation has clear pathways to seek professional consultation from an adequately qualified, registered and experienced clinician. Consider:  addressing personal beliefs  clinical, multidisciplinary advice  avoiding a sole medical perspective and treatment  interventions are evidenced-based. |
| Coherent service planning and sharing of information | The planning and delivery of services for the young person is undertaken in collaboration with all existing and proposed providers. There should be a single support plan which outlines interventions for SBoC. Consider:  involvement of parents  collaboration with all service providers  advocacy for individuals with disabilities who are subject to restrictive practices. |

These recommendations for organisational responses to SBoC comprise the core dimensions of PBS which are integral for enhancing quality of life and minimising challenging behaviour, including SBoC37.

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34–48. Interested readers should refer to this document for details of the methodology.

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