

IMPROVE and CARE: Responding to Inappropriate Masturbation in People with Severe Intellectual Disabilities

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Inappropriate masturbation frequently presents as a challenging behaviour in people who have intellectual disabilities. Responding to this behaviour requires an approach that considers the individual's reasons for the behaviour, and meets their individual needs. This paper describes a framework for responding to inappropriate masturbation based on principles of respecting the person's rights, dignity and individuality. The framework uses the acronyms IMPROVE (Investigate, Meet the need, Planned education, Redirection, Optimism, Versatility, Evaluation) and CARE (Consistency, Accuracy, Respect and Empowerment) to develop an approach to effectively address this behaviour.

KEY WORDS: masturbation; intellectual disability; inappropriate sexual behaviour.

INTRODUCTION

This article presents a framework for responding to inappropriate masturbation in people who have an intellectual disability. The framework has been developed to respond to the needs of children and adults with moderate to severe intellectual disabilities, but could be used in assisting people with mild disabilities, and may be applied to a range of inappropriate behaviour.

Inappropriate masturbation is a very sensitive issue which many care workers find embarrassing to discuss or address. Frequently it is treated with ridicule or simply ignored. Myths abound about the sexuality of people with intellectual disabilities. This often results in response to inappropriate behaviour

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being quite irrational and punitive. People with severe intellectual disabilities are often denied access to formal sexuality education, and often lack skills in communication, relationships and discerning the impact of their behaviour on others (1).

Over half of the referrals in 1994–1997 to Family Planning Queensland's one-to-one education program for people with intellectual disabilities were for people displaying inappropriate sexual behaviour. Of these, about 70% were referred because of inappropriate masturbation. This includes people who masturbate in public places, masturbate for long periods, masturbate to the point of self-injury, steals others' underwear to masturbate with, or become frustrated or violent after masturbating.

Frequently, care providers feel that their client requires education to stop them from masturbating inappropriately. However, as in all areas of health promotion, education alone does not result in behavioural change (2). A more comprehensive approach is required.

The framework for responding to inappropriate masturbation is based on three fundamental principles. These are:

1. Masturbation is a normal and healthy expression of sexuality.
2. All human behaviour communicates.
3. The least restrictive alternative should be used.

These principles are explored below.

MASTURBATION IS NORMAL AND HEALTHY

It is widely accepted in sexuality research that masturbation is a normal and healthy expression of human sexuality (3). Although some religious and conservative groups would disagree (4), research supports the assertion that most people engage in masturbation, and that it is a behaviour that occurs throughout the lifespan. It has been called "the safest sex of all" (5) and for a person who lacks the ability to discuss and negotiate safe sex, may be the only safe sexual option available.

In view of this attitude, it is crucial to emphasise that the response framework in this article is *not* a process that attempts to eliminate masturbation. Such approaches are not only unfair, but inevitably seem to fail (6). Indeed, if we wish to address inappropriate masturbation, it is essential to accept and even promote *appropriate* masturbation.

In some cases, care providers have an agenda not to prevent inappropriate masturbation, but to eliminate masturbation altogether. Obviously there are many reasons why this may be the case, not the least of which are the beliefs

that masturbation is sinful or wrong (7), or that the sexuality of people with intellectual disability is dangerous, deviant and must be suppressed. These attitudes are frequently internalised by the client as well (1). If these agendas are operating, it is important to address the carers' attitudes and to foster an environment in which the person with intellectual disability has their sexuality respected and accepted.

What is "inappropriate masturbation"? Hingsburger (7) suggests that masturbation is inappropriate if it:

- occurs in the wrong time or place
- causes injury to the genitalia
- is done so frequently that it interferes with regular activities
- occurs almost constantly.

Additional criteria could include:

- when it causes distress for others (e.g., causing hygiene problems, using objects such as stolen underwear, making excessive noise)
- when it causes distress for the person (e.g., frustration due to being unable to reach orgasm, extreme feelings of guilt).

ALL HUMAN BEHAVIOUR COMMUNICATES

This principle derives from the functionalist approach, which views all behaviour as serving a purpose for the person (8). This is an approach which acknowledges the rights of the person with an intellectual disability, and acknowledges that while we are not always able to understand the motivations and purposes of a person's behaviour, the person does usually have a reason for what they are doing.

Thus, addressing inappropriate masturbation successfully relies on an understanding of what the behaviour communicates about that person, or what purpose the inappropriate masturbation may be serving for them. If this understanding is lacking, approaches tend to be oppressive and punitive (6).

LEAST RESTRICTIVE ALTERNATIVE

The principle of least restrictive alternative is based on the assumption that using interventions which are more restrictive than necessary limit the dignity and independence of the person (9). To achieve this goal, a useful criterion to apply to interventions is to ask "Does this intervention result in an improvement

in the client's quality of life?" The framework presented here aims to assist the client to reduce or eliminate inappropriate behaviour by improving their ability and incentive to behave more appropriately. Therefore, punitive and restrictive approaches do not belong in this approach.

IMPROVE

Given that the aim is to improve the client's quality of life, the framework is represented as an acronym: IMPROVE, as shown in Figure 1. This stands for Investigate, Meet the need, Planned education, Redirection, Optimism, Versatility and Evaluation. Each of these should be viewed as principles for responding rather than sequential steps.

Investigate

A person who has a moderate to severe intellectual disability may not be able to tell us why they are masturbating inappropriately. Indeed, they may

I nvestigate	(thoroughly examine the situation to determine the causes of the behaviour)
M eet the need	(assist the person to meet identified needs in more socially acceptable and positive ways)
P lanned education	(a structured program of education which takes into account the individual's learning needs)
R edirection	(what is said and done by direct carers when inappropriate behaviour is observed)
O ptimism	(belief that the individual can learn and change their behaviour)
V ersatility	(willingness to try a variety of non-restrictive interventions)
E valuation	(structured monitoring of baseline behaviour and any changes which occur)

Fig. 1. The IMPROVE model.

have very limited or no verbal or other formal communication. However, using the principle that all human behaviour communicates, we can answer the question “Why is this behaviour occurring?” by thoroughly investigating the situation.

This step is often not carried out before intervention is attempted. One of the most common and unfortunate assumptions that is made is that inappropriate masturbation is the result of excessive/abnormal sex drive (7). Intervention based on this assumption may include the administration of Androcur or Depo Provera to boys and men, which rarely results in the desired change in the inappropriate behaviour. In addition, the use of such drugs raises an important issue of informed consent, as they would only be prescribed for men who don't have intellectual disabilities if they are intractable sexual offenders. Even among such men, many choose a custodial sentence rather than tolerate the effects of these drugs (10).

Instead of taking this very restrictive and intrusive approach, this framework proposes treating each person as an individual and trying to discern why that person is masturbating inappropriately. It can help to be aware of the wide range of reasons for masturbation and masturbation-like behaviour. These may include:

- a lack of knowledge or understanding of appropriate limits
- boredom, depression
- genital discomfort (due to irritation, infection, tight foreskin, tight clothing)
- seeking attention, or to annoy, impress, attract or win approval
- pain
- in response to traumatic sexual experiences
- inability to masturbate effectively/appropriately, e.g., due to
 - lack of privacy
 - poor technique
 - strong feelings of guilt
 - effects of medications

Identifying the motivation behind the inappropriate masturbation can be assisted by gathering information about the person's past history, living situation, medical history, what (if any) sexuality education they have received, where they masturbate, when, how often and for how long, how long it has been a problem, masturbation technique, any injury (present or past) and hygiene practices. It is important to also examine how the behaviour has been reacted to in the past, and the attitudes expressed toward the person and their behaviour by caregivers.

This is *not* to imply that people with intellectual disabilities do not have

sexual drives, or that they are mechanistic and that we can easily diagnose the cause of a particular behaviour. Instead, this approach acknowledges the complexity of masturbation and the diversity of purposes it can serve.

Table 1 presents some examples of inappropriate masturbation, and possible reasons for this behaviour. These are examples only, and there are an infinite variety of possibilities. Only careful consideration of the actual behaviour in the context of the client's individual circumstances will allow a reasonably accurate assessment to be made.

Meet the Need

When a comprehensive picture of the person and their inappropriate behaviour has been gained, the behaviour can often be seen as communicating that the person has one or several needs that are not being met. In the case of inappropriate masturbation, these needs may include any of the following:

- treatment of infection/irritation/tight foreskin;
- more comfortable/appropriate clothing;
- improved ability to communicate needs, seek attention or express emotions in a more appropriate way;
- adequate access to a private place which is comfortable and pleasant to be in;
- more activity options, social opportunities;
- more pleasant non-sexual sensory input, e.g., music, massage, swimming, "rough & tumble" play, bubble baths, scented oils;
- adequate unstructured time;
- elimination of factors in the environment which may be acting as "triggers";
- counselling;
- access to water based lubricant and/or sexual aids.

Attempting to meet these needs acknowledges that environmental factors can often have a significant positive or negative influence on a person's ability and motivation to behave appropriately (6). The key to success here is to intervene in a way which maximises the client's control and choices in their life.

It is important to acknowledge that meeting these needs may not in every case result in complete cessation of the inappropriate behaviour. However, by offering the person with a disability more positive life experiences and more control over their environment, this approach focuses on improving the general quality of the person's life. This gives them alternatives to the inappropriate behaviour and provides positive reinforcers for appropriate behaviour.

Table 1. Examples of Reasons for Inappropriate Masturbation

Situation	Investigation and Explanation
<p>A young man with severe physical and intellectual disabilities who masturbated for several hours every day in the classroom at school, frequently resulting in self-injury. He rubbed himself through his clothing, and no evidence of ejaculation was seen.</p>	<p>This young man had very limited ability to interact with others and he was unable to participate in classroom activities. He had little or no privacy at home and consequently had no opportunity for appropriate masturbation. He rarely masturbated when on an outing, or when someone was sitting talking to him on a one-to-one basis. The situation suggests that his behaviour was principally motivated by <i>boredom</i>. He also appears to be experiencing <i>sensory deprivation</i>.</p>
<p>A young woman with a moderate intellectual disability and autism who was learning community access skills who masturbated while waiting in the supermarket checkout queue. She would hold her vulva and rock back and forward, sometimes making a “keening” noise.</p>	<p>The noise this young woman was making was often associated with stressful situations. She often found it difficult to meet new people, and to touch others. When one care worker reacted angrily, she stopped briefly, but then started again, even more vigorously. This young woman seemed to be expressing that interacting with the checkout assistant was very <i>stressful</i> for her and she was anticipating this situation.</p>
<p>A young man who would go to his bedroom on arriving home from school, and masturbate for over an hour. He would become very frustrated, and would often emerge from his bedroom and be very violent toward others in the house.</p>	<p>This young man did not reach orgasm. He masturbated by lying face down on his bed with his clothes in place and rub against the bed. He had been institutionalised nearly all his life, and previous staff had punished him for touching his penis. His behaviour may have been related to <i>ineffective technique</i>, possibly due to <i>negative feelings</i> about masturbation.</p>
<p>A physically able man in his 60’s with a moderate-severe intellectual disability, living in a nursing home, who masturbated 12–20 times a day, in public parts of the home.</p>	<p>This gentleman was found to be on <i>medication</i> which had impairment of ejaculation listed as an adverse effect. As a result he was quite frustrated. It also transpired that he did not masturbate on outings or when he had visitors, suggesting that he was <i>bored</i> or <i>frustrated</i> with his living situation. Finally, he seemed to enjoy the <i>attention</i> he received when other residents reacted with shock to his behaviour.</p>
<p>A woman in her mid-thirties, who masturbated several times a day by squatting and rubbing her vulva on an area of rough ground outside the residential unit she lived in.</p>	<p>The woman’s co-residents frequently masturbated in public and most staff simply ignored the behaviour. She did not have her own bedroom, and had no day program of activities. She was found to have a severe thrush infection, and a dermatitis of the vulva. Her inappropriate masturbation may have been due to <i>discomfort</i>, a <i>lack of privacy</i>, a <i>lack of awareness of appropriate privacy</i> and <i>boredom</i>.</p>

Planned Education

Sexuality education takes place all the time, often unintentionally. We are all constantly receiving and sending messages about sexuality through our behaviour and relationships (11). For people with intellectual disabilities, much of their learning will also occur in this way. Unfortunately, much of this unintentional education about sexuality has the potential to impart negative or confusing messages to the individual.

In order to counter this effect, it is first important to acknowledge the learning that the individual has experienced and the sources of information they may have had. Common sources of learning include others' behaviour, punitive responses from staff or family, half-truths or lies which may have been told to the individual.

Given these confusing and negative sources of information, it becomes necessary to identify the specific information needs of the individual, and provide this information in a way which is of most use to the client. This may take the form of structured educational sessions, and/or regular input from carers in everyday life. People with intellectual disabilities will generally respond best to educational interventions which are short, focussed and which make use of "teachable moments"—significant events in the individual's life which naturally focus their attention on the topic of education. Education should have clear goals, be tailored to the individual's needs and use consistent, simple, repetitive language.

Areas of education that may need to be addressed include:

- body parts and sexual functioning;
- public and private;
- positive attitudes toward appropriate masturbation;
- how to masturbate safely, hygienically and effectively;
- expressing feelings appropriately.

It is preferable if this information can be presented in a context of human relations education, and reinforced in the day-to-day interactions of the person's life. Resources for education need to be explicit and clear. Three dimensional models, line drawings and photographs are often very useful. It is extremely important that educators undertaking this sort of education inform themselves of the legal issues surrounding this contentious area.

Although this stage is a crucial part of the response framework for any individual, it cannot stand alone. One could argue that it is cruel to provide some individuals with education without addressing the other needs in that person's life. For example, teaching someone that they may masturbate in private

places when their living situation allows no privacy sets them up to fail and may only increase their frustration.

Redirection

Redirection refers to what is actually said and done by caregivers when a person behaves inappropriately. This could be seen as the most frequent and effective form of direct education, as it is clearly linked to the event. Unfortunately, the initial reaction of carers to inappropriate masturbation can often reinforce the behaviour, or result in guilt, fear and frustration.

Because every situation is different, no one redirection technique will work with every client. Some clients will only require a verbal prompt, others may need a combination of verbal, visual and physical redirection. There will be situations in which it is more appropriate to redirect a person to a more appropriate place, while other situations may call for redirection to a more appropriate activity.

Given the negative associations that masturbation has, it is important that whatever type of redirection is needed, the response should be caring. Using the acronym CARE, I suggest that redirection should reflect the principles of Consistency, Accuracy, Respect and Empowerment. Figure 2 demonstrates how CARE fits into the IMPROVE model.

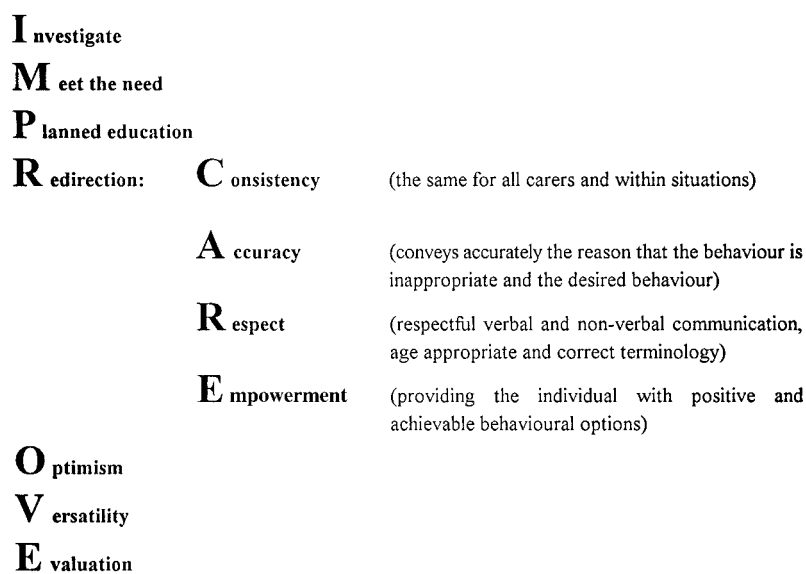


Fig. 2. The IMPROVE and CARE models.

Consistency

Consistency requires that all carers respond to the inappropriate masturbation in the same way 100% of the time. Others in the same environment should receive similar responses if they display similar behaviour. Obviously, the redirection will change if someone masturbates while standing in the doorway of their bedroom compared with if they are standing in the doorway of a supermarket. *Within* each situation, however, the response should be consistent.

Accuracy

I recently met a group of young men with mild intellectual disabilities who believed that masturbation would make their penises fall off! This misconception was due no doubt to a misguided attempt on the part of their caregivers to stop them from masturbating in inappropriate places. We spent a large part of the session then discussing why their caregivers had told them lies!

Obviously, redirection should avoid the use of myths (e.g., you'll go blind, it'll drop off etc). Although most adults today have heard these myths and survived to become relatively well-adjusted sexually, people with intellectual disabilities may not be able to apply the same standards of disbelief to information they receive from those they trust. Using inaccurate messages will only serve to confuse and upset the client, and will not address the behaviour effectively.

Accuracy also implies that the redirection should give as clear a message as possible about why the behaviour is inappropriate (e.g., not a private place). While simple language is important, the one word responses "No!" or "Don't!" are easily interpreted as a general prohibition against masturbation, rather than a redirection towards a more appropriate expression of sexual behaviour.

Respect

Language used should be age-appropriate and attention should be paid to tone of voice, volume, body language, and avoiding "put downs." Respect implies using discretion in response in public places. This should not be read as supporting an approach of ignoring the behaviour, but instead using redirection which does not draw the public's attention to the inappropriate behaviour. While redirection may at times have to be quite firm, this should never stop it from being respectful.

Empowerment

This principle is really the basis for the whole of the IMPROVE-CARE framework. The redirection should provide positive options for appropriate behaviour which are realistic for the individual. A useful strategy may be to avoid the word “don’t,” and seek to explain to the client what they *can* do in the situation.

For example, the response “Don’t touch” is neither clear, nor empowering. If the client was at the supermarket, a more empowering redirection may be “Here Jane, push the shopping trolley now please.” On the other hand if she were in the kitchen at home, it may be, “You can do that in your bedroom with the door shut. Go to your room, please.”

The redirection process can be demonstrated by reference to an example of Jeff,³ a young man with autism and a severe intellectual disability who lived in a large residential establishment. While his expressive language is very limited, he seems to understand a good proportion of what is said to him. Jeff would frequently masturbate while sitting in front of the T.V. in the lounge room. The staff were very accepting of masturbation and would say to Jeff, “Go to your room, Jeff,” whereupon he would go to his bedroom, climb into the wardrobe and shut the door behind him, and stay there until staff asked him to come out. It did not appear that he was masturbating in the wardrobe.

The reasons for Jeff’s behaviour are not immediately obvious, but given his life history, it is possible that he had been punished by past staff by being locked up and had internalised the attitude that he should be locked up for “bad” behaviour. Another possibility is that he was seeking the most private place he could find.

Either way, it is clear that the redirection given was not effective for Jeff – it was not accurate, in that he did not understand what it meant, and it was not empowering in that it did not teach him a positive option for his behaviour. The solution found was that staff were to say to him, “Jeff, you can play with your penis lying on your bed,” and accompany him to his bedroom door, gesture toward the bed, and then leave him in privacy. Basically, Jeff needed permission to enjoy appropriate masturbation.

Optimism

Resistance to providing any human relations input for people with intellectual disabilities often seems to be based on the false assumption that “They can’t learn.” Brown (12) discusses this pessimism as a major factor leading to restrictive approaches to the sexual lives of people with disabilities.

³Not his real name.

One response to this attitude is to point out that if a person is displaying an inappropriate behaviour then they have learnt it. It is a behaviour with which they are addressing, or attempting to address their own needs. This demonstrates that they *can* indeed learn, which places the onus on their caregivers to discover how to best facilitate learning of the desired behaviour. Another approach is to discuss with the carers all the things that the individual has learnt to do, and the approaches that have been useful in teaching them.

Another statement frequently associated with the sort of interventions suggested in this article is, “We tried that, it didn’t work.” Because of the controversial and embarrassing nature of inappropriate masturbation, it may be tempting to seek a “quick fix,” an attitude which many medical practitioners are willing to accommodate. People with intellectual disabilities *will* take longer to learn than others—this is not a reason to give up on them. I often find it useful to remind carers of the amount of time they allowed for the person to learn such concepts as basic hygiene and road safety. The use of medication to suppress sexual behaviour, aversive conditioning, restrictive clothing and other restrictive approaches is a reflection of an underlying pessimism about the person’s ability to learn.

Versatility

The framework described here depends on using informed guesswork to understand the motivations, intentions and history of people who are often unable to communicate clearly. As such, it is likely that some incorrect assumptions will be made. Therefore it is important that a range of options for intervention are considered.

Having stressed the importance of optimism, it is clearly important to recognise when an approach is not working. One young man had been prescribed oral Provera for four years, and the inappropriate masturbation he displayed had not changed in any way. Despite this, his caregivers were reluctant to see him stop taking these tablets.

Evaluation

Any intervention program needs to be carefully evaluated. In order to be fair to the person, it is important to record and acknowledge any improvement in their behaviour, however small this may be. Robison, Conahan and Brady (6) describe a process of gaining an accurate, quantified measure of the “baseline” or pre-intervention level of inappropriate masturbation. If the inappropriate behaviour is not changing, it may be necessary to more thoroughly investigate the behaviour, or alter the responses to more accurately meet the individual’s needs.

CONCLUSION

This approach to responding to inappropriate masturbation is based on experience working with clients with severe intellectual impairments. The framework views the problematic behaviour in a realistic context of the person's life, and responses are based on respecting and empowering the client. It is a framework which may be used to work with a wide variety of clients, in addressing not only inappropriate masturbation but a range of other inappropriate behaviours.

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