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ORIGINAL PAPER

The Content, Usefulness and Usability of Sexual Knowledge Assessment Tools for People with Intellectual Disability

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Abstract Many people with intellectual disability have limited sexual knowledge. Several assessment tools have been developed to assess the sexual knowledge of people with intellectual disability. This paper examines clinicians' perspective on the usefulness and usability of these tools. This research uses a constructionist grounded theory approach. Semi-structured qualitative interviews were conducted with clinicians who use sexual knowledge assessment tools. To provide a context for clinicians' comments about these tools, this paper also provides a content analysis of six sexual knowledge assessment tools. Several themes emerged from the interview data; (a) clinicians want to use sexual knowledge assessment tools to support their work, (b) clinicians want more guidance in relation to administering these tools, and (c) clinicians have concerns about the usefulness and usability of sexual knowledge assessment tools.

Keywords Sexual knowledge assessment tools · Intellectual disability · Sexual health · Australia

Introduction

The first World Report on Disability identified that "sex education is important to promote sexual health and positive experiences of sex and relationships for all people with disabilities" [1]. Yet, many people with intellectual disability have not received any formal

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sexual health education and, as a result, have limited sexual knowledge [2, 3]. Limited sexual knowledge has been identified as a major barrier to optimal sexual health for people with intellectual disability [2, 4, 5], which can lead to negative and even life-changing outcomes. For example, poor sexual knowledge has been linked to higher rates of sexually transmissible infections, with rates of infection up to eight times higher in men with intellectual disability than those without [6]. In addition, higher numbers of unplanned pregnancies and more negative feelings about sex are also widely reported in the literature as being associated with poor sexual knowledge [3, 7, 8].

Recent years have seen an increasing expectation that disability service providers will address the sexual health needs of people with intellectual disability and assist them to overcome the barriers to optimal sexual health [2, 7, 9]. However, in a companion paper we found that disability service providers and clinicians experienced their own barriers to sexual health service provision, such as lack of staff training and the negative attitudes of others [5]. The barriers that interfere with disability service providers and clinicians meeting the sexual health needs of their clients can serve as additional barriers for people with intellectual disability, and thus warrant exploration. Thompson et al. [5] found that one such barrier was the perceived effectiveness of currently available sexual knowledge assessment tools.

Thompson et al. [10] found that clinicians in the Australian state of New South Wales (NSW) primarily utilize sexual knowledge assessment tools to inform reports on the sexual health knowledge of individuals with intellectual disability and to develop sexual health education programs for them. Moreover, data analysis revealed that the process of having a sexual knowledge assessment usually served as the sole access point to a sexual knowledge education program [10]. This study also found that clinicians placed a heavy emphasis on the topics and content included in sexual knowledge assessment tools when developing their sexual health education programs [10]. Therefore, the content of sexual knowledge assessment tools directly influences what information people with intellectual disability will be exposed to in sexual knowledge education programs. Thus, the content of these tools is central to how useful clinicians find sexual knowledge assessment tools for assessment and education.

The two main tools being used by clinicians in NSW, Australia are The Human Relations and Sexuality Knowledge and Awareness Assessment: for People with an Intellectual Disability (HRSKAAP-ID) [11] and The Assessment of Sexual Knowledge (ASK) [10, 12]. Both of these tools were developed in Australia. Based partly on analyses of interviews with clinicians in NSW, this qualitative study will examine the following issues: (a) the content of sexual knowledge assessment tools (b) the usability of sexual knowledge assessment tools, and (c) how useful clinicians find these tools.

In addressing the first issue we recognise that, in addition to the two tools used in NSW, other sexual knowledge assessment tools are available for people with intellectual disability. To ensure that we provided a more comprehensive content analysis and to make this paper more relevant to clinicians in other jurisdictions, we broadened our content analysis to include four other tools, (a) Sexual knowledge, experience and needs scale for people with intellectual disability (SexKen-ID) [13], (b) Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised (SSKAAT-R) [14], (c) General Sexual Knowledge Questionnaire (GSKQ) [15], and (d) Sexual Knowledge and Behaviour Assessment Tool (SKABAT) [16], the last three of which were developed outside Australia. The additional tools were chosen because they were in use in various countries around the world and some published research was available about each tool.

Like many assessments designed specifically for people with intellectual disability, these sexual health assessment tools have attempted to use simple, concrete words, short sentences and pictures to help people with intellectual disability understand the questions [17]. For example, the SSKAAT-R [16] asks short questions such as 'Can a man have an orgasm?' Likewise, only simple responses are required to answer certain questions, such as in the public and private section of the HRSKAAP-ID [11] where the person being assessed is asked to point to the public and private places thus making these questions easier to answer for individuals with limited expressive language.

Method

Ethics Approval and Consent

The research was approved by Human Research Ethics Committee at the University of Sydney.

Content Analysis of Tools

A content analysis was conducted on the tools used by clinicians in NSW, Australia, HRSKAAP-ID [11] and (ASK) [12]. Other available sexual knowledge assessment tools for people with intellectual disability-SexKen-ID [13], SSKAAT-R [14], GSKQ [15] and the SKABAT [16]—were also included in the content analysis to provide a comparison and to increase the relevance of the paper to readers outside Australia. This analysis involved comparing these six sexual knowledge assessment tools in relation to their framework, guidelines, topics, questions and use of pictures.

Participants

Purposive sampling was initially used to recruit the participants. Following the analysis of earlier interviews, theoretical sampling was employed to explore emerging categories and their properties. Strauss and Corbin [18] suggest that the adequacy of theoretical sampling is judged by the breadth and diversity of data which the researcher selects for building theory. Engaging in theoretical sampling resulted in a range of participants (clinicians) from different locations (9 urban vs. 14 regional/rural), programs, levels of experience and backgrounds. Data collection involved conducting face-to-face semi-structured interviews with a total of 23 clinicians (clinicians A to W; 8 males; 15 females) who worked directly with people with intellectual disability in relation to their sexual health, including those directly employed by disability service providers ($n = 19$), as well as clinicians in private practice ($n = 4$). A range of disability programs were represented including; employment, accommodation, community services and behaviour support. Twelve participants had postgraduate qualifications, 7 had undergraduate degrees, and 4 had vocational-type certificates or diplomas. Clinicians' self-reported that the percentage of the overall time in their job role taken up by the sexual health of people with intellectual disability varied from 2 to 95 % across individual clinicians. Experience in the disability sector ranged from 2 to 32 years. Five participants had less than 5 years' experience, 3 had 5–10 years' experience, 1 had 10–15 years and 14 had greater than 15 years' experience. The clinicians had a range of backgrounds including; teaching, nursing, psychology, disability, and sexual

health. The clinicians' job titles included; psychologist, behaviour intervention support specialist, counsellor, educator and registered nurse. All of the clinicians interviewed were identified by their managers to be experienced in the use of sexual knowledge assessments. Despite this claim, four of the clinicians interviewed had never used a sexual knowledge assessment tool. This did not become apparent until the time of the interview. Private practitioners were identified by managers who sought external input to assess the sexual knowledge of their service users.

Interview Guide and Technique

Consistent with constructivist grounded theory, the qualitative method of semi-structured interviewing was used. This was to allow the participants opportunities to provide comprehensive answers to open-ended questions and to identify and explore issues that were of relevance to their experiences [19, 20]. Questions in the interview guides were initially developed from a literature review, supplemented by clinical experience, and then piloted with colleagues experienced in sexual health provision. Using constructivist grounded theory allowed for new themes brought to light in earlier interviews to be explored in subsequent interviews.

The initial interview guide contained 25 questions. As new categories emerged and explored the interview guide was expanded. The final interview guide contained 43 questions divided into three sections including; clinician demographics, the context of working with people with an intellectual disability in relation to sexual health, as well as the practical application of sexual knowledge assessment tools. Example questions included; 'What are your thoughts about the sexual health knowledge assessment tool you use?, How effective do you think the tool you are using is? Thinking about the assessment tool you are using now could you comment on the topic areas of the tool? and 'How well do you think the sexual knowledge assessment tool is meeting the needs of people with intellectual disabilities?' Due to the evolving nature of the interview guide not all questions were asked of each clinician. Consistent with qualitative interview techniques, questions that were not part of the interview guide were asked when exploring emerging themes with clinicians as appropriate.

All participants provided written informed consent prior to interviews; verbal consent to digitally record the interview was given prior to commencing. Interviews with clinicians lasted between 45 and 90 min. Interviews were audio recorded, and then transcribed verbatim to allow for comprehensive data analysis.

Analysis of Interview Data

The transcripts of the interviews were analyzed using a constructivist grounded theory approach. Transcripts were read using a constant comparative method to enable the emerging themes and issues to be identified and then grouped into broad categories [20]. Analysis occurred throughout the data collection and sampling continued until theoretical saturation was reached and no new themes or ideas emerged from the data [20]. Analysis was conducted by the first author with transcripts checked by the rest of the research team to ensure trustworthiness. The research team consisted of researchers from different backgrounds (sexology, psychology, sociology and nursing) thereby offering different perspectives on the analysis of the data. Findings were presented at a national conference with feedback provided by peers [21]. A final draft of the paper was sent to participants for review against the credibility criteria of originality, credibility, resonance and usefulness

proposed by [20]. Participants that provided feedback endorsed the paper and no amendments were indicated.

Findings and Discussion

Several themes emerged from the interview data in relation to clinicians' perceptions of the usefulness and usability of sexual knowledge assessment tools: (a) clinicians want to use sexual knowledge assessment tools to support their work, (b) clinicians want more guidance in relation to administering the tools, and (c) clinicians have concerns about the quality of sexual knowledge assessment tools. The following discussion looks at these themes in more detail.

Clinicians Want to Use Sexual Knowledge Assessment Tools to Support Their Work

Foundation Clinicians reported that sexual knowledge assessment tools provided them with a useful foundation from which to base their work. The tools contain topics and questions which at the very least prompt the clinician as to what areas they should consider assessing.

> Well I suppose if I was to talk about the ASK, it provides a starting point to explore peoples' understanding, at least there's some pictures in there that can help people to understand the questions (Clinician M).

Topic Division Clinicians expressed that they liked that the two tools were both broken up into different topics. This allowed them to choose what areas they assessed and to obtain information on certain topics if required. The division of the tools into topics also means that clinicians can stagger the assessment process over a few sessions with people with intellectual disability, which may be useful to counter interview fatigue thus potentially leading to more reliable responses [22].

> I would have to say that it's the ability for us to be able to break it up into the different areas and only ask about specific areas is what I like about it, so you know when you want to look at attitudes only you don't have to put the person through the whole assessment if you want to just assess their knowledge at a really brief level of understanding. (Clinician O).

All six sexual knowledge assessment tools we analyzed had distinct topic areas.

Supports Clinician Participants viewed their use sexual knowledge assessment tools as helping to 'legitimise' clinicians' work and recommendations on the sexual health of people with intellectual disability to other staff and family.

> So I think it's important you base [reports on sexual health knowledge] on evidence. You administer these [sexual knowledge assessment tools] and it's like, these are the tools and this is the percentage and the score so when you use the tools [those supporting people with intellectual disability] have a more of an understanding than when you're just talking about something. The tools let people know you're not just making your reports and stuff up (Clinician N).

Psychometric Properties Some clinicians found the face validity and inter-rater reliability of ASK [12] to be valuable.

> Because [the ASK] is a valid tool, we want to use that to guide our curriculum (Clinician Q).

Clinicians seemed impressed that data on some psychometric properties were reported in the ASK [12] but were uncritical of the quality or comprehensiveness of these data. Table 1 highlights the reported psychometric properties of the six sexual knowledge assessment tools, grouped separately for the two tools used by participants in the current study and the four other available tools not used by study participants. The term 'responsiveness' (Table 1) relates to the proportion of items to which individuals with intellectual disability are able to provide a scorable answer. All tools with the exception of the HRSKAAP-ID [11] and the SKABAT [16] report data on at least some psychometric properties.

Clinicians Want More Guidance in Relation to Administering the Tools

Not enough Information Clinicians perceived that the tools did not provide enough information from which to complete a comprehensive report or to develop a sexual health education program. Yet, despite these reported limitations, in the absence of something more suitable clinicians typically persisted with using sexual knowledge assessment tools to form a base for their work.

> I think in some ways the [sexual knowledge assessment tool] was a great deal better than nothing (Clinician C).
> [Sexual knowledge] assessment tools are useful but they are only one small part of the process. By themselves they're useless (Clinician A).
> I think [the sexual knowledge assessment tools] don't get to the depths that we necessarily need if we're going to do a true assessment of people (Clinician M).

The additional methods clinicians used to inform sexual health education programs or reports varied based on their experience, access to resources and training. Some clinicians were somewhat uncertain as to what else to use to inform the sexual health education programs, whereas seemingly more experienced clinicians had clearer ideas on what they could use. This variation in approach means that the outcomes for people with intellectual disability could vary greatly depending on the clinician who assessed them.

> *Q. What other methods did you use to inform the sexual education program?*
> Um, I guess it would be a little bit of, um, sort of the lifestyle and environment review and, um, behavioural assessment or whatever it might be from organization to organization (Clinician C).
> …there are many ways I gather information. One of them might be from doing a family tree, another one might be doing a map of where people have lived and who they've lived with…I also use Teach Bodies to compliment the ASK for certain people, um, children and clients who have limited communication skills (Clinician F).

The sexual health knowledge of clinicians, as well as their own attitudes, impact on their ability and willingness to be able to provide comprehensive sexual knowledge assessments [10, 23]. None of the tools analyzed provide clinicians with information on how or where they could access more information to inform the sexual knowledge assessment process.

Table 1 Sexual knowledge assessment tools-psychometric properties

Psychometric property	Sexual knowledge assessment tool					
	Used by participants		Not used by participants			
	HRSKAAP-ID [11]	ASK [12]	SexKen-ID [13]	SSKAAT-R [14]	GSKQ [15]	SKABAT [16]
Validity	×	Face	×	✔	×	×
Reliability						
Test–retest	×	✔	✔	✔	×	×
Inter-rater	×	✔	×	✔	×	×
Split half	×	×	×	×	✔	×
Internal consistency	×	×	×	✔	✔	×
Responsiveness	×	×	×	×	×	×

Not Enough Guidance to Prepare People with Intellectual Disability Clinicians reported that the tools do not give them enough guidance to enable them to prepare people with intellectual disability about the nature of the assessment tool and what this process will involve.

> The manual is quite limited in how to prepare the person that you're going to give the assessment [to]. A couple of [clinicians] have given it here, and the people [with intellectual disability] have refused to participate it in once you get to the really explicit photos. There's very little advice I see in the manual about how to prepare with the person [with intellectual disability] for the material which is quite explicit (Clinician V).

This issue could be a result of lack of sexual health education training for clinicians, which would be consistent with previous research findings which have found lack of sexual health education training to be an issue in sexual health provision for people with intellectual disability [5, 9]. Nevertheless, clinicians do still want more guidance from the assessment tools. All six tools reviewed lack guidance on how to prepare people with intellectual disability prior to being exposed to the sensitive material in the sexual knowledge assessment tools.

No Guidance After Administration Clinicians expressed concern that neither the HRSKAAP-ID [11] or the ASK [12] offered any guidance on what to do after completing the assessment process.

> I don't think it really guides you then what to do after you've assessed (Clinician O).

This desired feature is absent from all six sexual knowledge assessment tools analyzed.

Clinicians Have Concerns About the Quality of Sexual Knowledge Assessment Tools

Response Bias Clinicians raised concerns about response bias and acquiescence which are common features of interviews with people with intellectual disability [23].

> So the one thing you have to be sure is that when you ask a question you can't just accept the answer because if you do you're just getting what you want. What's a public place, what's a private place "my bedroom", so you tick that, he scores 2 for that but in fact is that just a response and that really worries me because I think sometimes things are driven by that. You have to ask, does this mean anything this person? (Clinician A).

Neither the HRSKAAP-ID [11] or the ASK [12] provide information, training or techniques to enable clinicians to manage or assess response bias. None of the sexual knowledge assessment tools analyzed assisted clinicians with these issues.

Misinterpretation of Results Clinicians' reported that they were worried that the results of the sexual knowledge assessment tools could be misinterpreted, with significant negative consequences for people with intellectual disability, especially given the purpose of administering assessments is often to deem if a person is deviant or not.

> *Q. So what are your thoughts on the ASK?*
> Well I suppose it's the only one I sort of truly sort of know. It's alright, unfortunately I find if I really wanted to I could distort it a bit but I suppose this is an honesty sort of thing.

> *Q. What do you mean distort it?*
> I suppose the attitudes, not the knowledge component; it's more the attitudinal component. I think writing the assessment is the hardest thing about the actual assessment, not the actual answers they give and the actual assessment itself, the difficult thing is actually writing the assessment I find. I suppose because the whole way through sexuality is still sort of a taboo area. There is a bit of fear or worry about repercussions from what you might write [in a report] (Clinician L).

While misinterpretation is a risk for all assessments, the apparent lack of training clinicians receive in relation to sexual health [5] and the lack of training clinicians receive to administer the tools [10] combine to make the results of sexual knowledge assessment tools more open to misinterpretation. The fifth row of Table 3 reveals that none of the sexual knowledge assessment tools come with training or accreditation to enable the clinician to administer the assessment correctly. Every page of the picture booklet in the ASK [12] states:

> The pictures in this Picture Booklet are intended for use by trained administrators applying the Assessment of Sexual Knowledge according to the purposes and instructions outlined in the accompanying documents 'A sexual knowledge assessment tool for people with an intellectual disability and Administration Manual'

However, nowhere in the tool does it inform a clinician how to become a 'trained administrator' of the tool or what is required to fulfil this role.

Concern Over Prompts in the ASK The ASK [12] sets out prompts for each of the questions. Clinicians expressed concern that these prompts did not necessarily provide them with opportunities to gain a response from people with intellectual disability that accurately portrayed their knowledge.

> If you're going to use the ASK and you're going to use it as it's designed you will ask the question, you will give one hint and then you will mark accordingly, and you know and I know that you might or you might not and be getting a reasonable view (Clinician A).

Despite the recognition that the prescribed prompts may not lead to accurate assessment results, clinicians were reluctant to step away from the prompts within the tool and questioned their own clinical judgement when they did.

> Again, it comes down to the client's communication; when you ask the question, and then you need to give the client time to answer, but sometimes you have to end up rephrasing and then you sit there and think, "Oh God, did I just rephrase that right?" You worry whether or not your question led to an answer they didn't intend to give. Sometimes there's not that level for the next level down in communication (Clinician P).
>
> I suppose there's that not stepping away from the assessment. It feels like if you ask a question, the question says don't prompt and you prompt "oh great, does that mean I've just turned this guy who likes to masturbate fortnightly to a deviant or something" (Clinician L).

Not Practical Enough Clinicians reported that the assessment tools were not practical enough and that the absence of a practical component within the tools made it difficult to engage people with an intellectual disability in the assessment process.

> I find that our clients have a difficulty in generalizing, so I have to make sure that they aren't just used to the pictures in [the assessment tool] and that they are able to apply it to different areas. I also use pictures from magazines, and I get them to practise themselves. I draw pictures for them as well, and I get them to point, just so I know that they really understand, and they have a good concept of where people can touch you, what times, and how they should ask if they want to touch you and if you want to touch them… I've also developed little pictures to say private public, and then I've got to go and actually label places where private is and where public is because that's a bit more practical than just going through a book and talking through things. I think that's the gap in the ASK. I think it needs to be more practical. A lot of clients don't understand pictures, which makes it difficult as well (Clinician Q).

The SSKAAT-R [14] (not used by the clinicians interviewed) contains two optional practical components; condom putting on and sanitary pad placement.

Score in Assessment Does Not Necessarily Reflect Generalised Knowledge Clinicians expressed concern that scores that people were given in sexual health knowledge assessment did not necessarily correlate with whether or not they had a true understanding of the content and whether they were able to apply this knowledge to real-life situations.

> So we did knowledge and awareness assessment. He understood it all, but when he came to himself he didn't understand it and he did not know how to put [a condom] on. So he knew it generally but he couldn't personalise it. But the knowledge and awareness [assessment] did not tell us that so we had to [find out] differently (Clinician B).

Outdated The age of the sexual knowledge assessment tools was a prominent issue for clinicians, with even the newer of the two assessment tools they used, the ASK [12], being over a decade old. Consequently both tools have not addressed the more recent rise in pornography and sex via the internet over the past decade (see Table 2). Likewise, with the introduction of new contraceptive methods and different terminology for sexually transmissible infections, other important changes have taken place since the publication of the HRSKAAP-ID [11] and the ASK [12].

Table 2 Components of sexual health in sexual knowledge assessment tools

Component of sexual health	Sexual knowledge assessment tool					
	Used by participants		Not used by participants			
	HRSKAAP-ID [11]	ASK [12]	SexKen-ID [13]	SSKAAT-R [14]	GSKQ [15]	SKABAT [16]
Awareness						
Public/private	✔	✔	✔	✔	×	✔
Relationships	✔	✔	✔	✔	×	✔
Sex. preference	×	✔	✔	✔	×	×
Gender identity	×	×	×	×	×	×
Communication	×	×	✔	×	×	×
Legal issues	✔	✔	×	✔	✔	✔
Stage of life issues						
Body parts	✔	✔	✔	✔	✔	✔
Puberty	✔	✔	✔	✔	✔	✔
Menstruation	✔	✔	✔	✔	✔	✔
Pregnancy	✔	✔	✔	✔	✔	✔
Menopause	×	✔	×	✔	×	×
Sexual activities						
Masturbation	✔	✔	✔	✔	✔	✔
Intercourse	✔	✔	✔	✔	✔	✔
Pornography	×	✔	×	✔	×	×
Sexual aides	×	×	×	×	×	×
Sex workers	×	×	×	×	✔	×
Other activities	×	✔	✔	✔	×	×
Wellbeing						
STIs	✔(STDs)	✔	✔(STDs)	✔	✔(STDs)	✔
Safer sex	×	✔	×	✔	×	×
Contraception	✔	✔	✔	✔	✔	✔
Screening tests	×	✔(some)	×	✔	×	×
Dysfunction	×	×	×	×	✔(male)	×
Pleasure	×	×	×	✔		×
Pain	×	×	×	×	×	×
Sex and technology						
Sexting	×	×	×	×	×	×
Internet	×	×	×	×	×	×
Sexual response cycle						
Libido	×	×	×	×	×	×
Arousal	×	✔	×	×	✔(male)	×
Orgasm	✔	✔(male)	✔	✔	✔(male)	✔
Number (%) of components covered (of 29)	12 (41 %)	19 (66 %)	14 (48 %)	19(66 %)	13 (45 %)	12 (41 %)

> And I think it is out of date too with a lot of the terminology and the information and stuff like that like STDs instead of STIs. And the contraception section, there's a lot of new contraception now so it is quite old, yeah (Clinician B).

It would appear important for these tools to be updated regularly to ensure that such issues are both assessed and addressed in educational interventions as needed.

Topics Many clinicians reported they were happy with the topics contained in the sexual knowledge assessment tools.

> *Q. What do you think of the topics of the tool?*
> Well, I would have to say it covers basically everything (Clinician V).

Most use the topics of the tools as a basis for their sexual health education programs and do not deviate from these topics.

> *Q. How influential is the assessment tool in determining what topics you'll use in the education program?*
> It forms a large part. I guess it's a standardised measure of what we can teach and what we shouldn't (Clinician R).

When initially asked, many clinicians thought the content topics of the assessment tools were comprehensive and did not think they should include any more topics than they already contain, but with prompting were able to recognise that the assessment tools were missing significant areas.

> *Q. Are there any other topics you would include?*
> I'd have to say no.
>
> *Q. What about things like sexual dysfunction or sex and the internet?*
> Yeah, you're probably right. Really when you think about it the tools are a bit dated aren't they? They haven't kept up with the technology. Because you're right, when you think about it, one of the issues that I've worked with a person, they were Facebook stalking and texting someone, so on a relationship level perhaps there does need to be some more about technology (Clinician M).

Table 2 shows which components of sexual health the sexual knowledge assessment tools address through their various topics as well as others they fail to address. A 'tick' indicates that the topic is addressed, not that it is covered comprehensively. For example, the GSKQ [15] is the only tool that addresses sexual dysfunction, but it only deals with one part of sexual dysfunction, impotence. It does this through the use of one question only and asks 'what is impotence?' It fails to address the causes of impotence or what someone could do if they experience it. It also does not look at other areas of male sexual dysfunction such as premature ejaculation, peyronie's disease, and retrograde ejaculation. No female sexual dysfunctions, such as vaginismus or dyspareunia, were covered by any sexual knowledge assessment tools. It follows that the issues that were absent from the tools were not assessed, so related misunderstanding or gaps in knowledge were not identified. Similarly, while all six tools covered male orgasm on some level, only four of the tools included questions about female orgasm. Moreover, male orgasm was only addressed from an ejaculatory perspective, and there was no attention given to prostate orgasms.

Table 2 highlights that several fundamental components of sexual health were missing from each of the sexual knowledge assessment tools analyzed. As the bottom row of the table shows, the six tools reviewed only covered between 41 and 66 % of the components of sexual health listed. This oversight is also a significant issue given most clinicians'

heavy reliance on the topics of sexual knowledge assessment tools for determining the content of their sexual health education programs. Consequently, issues such as sexting, sex and the internet, sexual aides such as use of vibrators and dildos, and sexual pain are likely completely absent from the sexual health education programs designed or delivered by participants in this study.

Pictures The sexual knowledge assessment tools analyzed used line drawings to supplement the questions. HRSKAAP-ID [11] and SexKen-ID [13] also contained two black and white photographs (of different forms of contraception). The SSKAAT-R [14] contained 17 photographs. Table 3 sets out the number of pictures contained in each of the tools.

Clinicians expressed concern that the sexual knowledge assessment tools did not contain enough pictures to enable them to determine whether people with intellectual disability did not possess knowledge in the area being assessed or whether they could simply not relate to the image being shown.

> *Q. What did you think of the pictures in the tool?*
> Look I thought they were, I guess as I said they were far more useful than nothing at all…I think a lot of the times you kind of go through the assessment and say "well you don't know about" tick the box and move on but perhaps people might give a response that perhaps conveyed that they didn't really understand what the—the picture was about. Um, um, or perhaps it might be that the picture was, um, specific to an environment, um, yeah, I guess it comes down to how you present the material think we definitely need to present the information across a whole range of areas, so whether it's 15 pictures of people masturbating in different environments or in different ways or whatever, then perhaps one of those might strike a chord with the person that we're working with that says "you know what that's what masturbation means to me" (Clinician C).

Table 3 Features of pictures in sexual knowledge assessment tools

Picture feature	Sexual knowledge assessment tool					
	Used by participants		Not used by participants			
	HRSKAAP-ID [11]	ASK [12]	SexKen-ID [13]	SSKAAT-R [14]	GKSQ [15]	SKABAT [16]
Number of						
Line drawings	41	22	13	18	2	20
Photos	2	0	2	17	0	0
Depict diversity in						
Sexual orientation	×	✔	×	✔	×	×
Age	×	×	×	×	×	×
Cultural group	×	×	×	✔	×	✔
Body type	×	×	×	×	×	×

Many clinicians supplemented the pictures in the sexual knowledge assessment tools with other pictures from resources they had. None of the tools provided information as to where additional pictures could be sourced, meaning the quality of the assessment again came down to training and access to resources of individual clinicians.

> Some of the pictures weren't clear enough, it didn't match the information we were trying to get. So we actually got some other pictures and visual aids that were clearer I think around representing what we wanted to know for the person (Clinician B).

Clinicians also expressed concern that the pictures in the sexual knowledge assessment tools were sometimes confusing for people with intellectual disability, meaning that an accurate assessment result was difficult to achieve.

> I know there was one of the masturbation sort of questions and it was quite funny because it must have been the male sitting down on the bed and you ask the question "what is this person doing" and the client said "oh he's eating a hotdog". Yeah, I suppose in one way if you'd looked at it, it looks like he is lying in bed just about to eat a hotdog (Clinician L).
>
> Some of the pictures, I've had clients that find it really difficult to tell the difference in the picture between the child and the adolescent, so they will kind of point at the child because maybe they're 18 and cognitively they're 12 and so in their mind they're looking at the child and so then there's education to do around that but when you talk further about that that's not something that they'd necessarily be attracted to just the way that the question's framed. It's the same between the adolescent and the woman I suppose or the grown up, the adult, there's not a lot of difference there in terms of the picture (Clinician O).

Another concern expressed by clinicians was that for some of the topic areas there were too many pictures on the one page which again can cause some confusion for people with intellectual disability.

> The pictures are quite good except that for some pictures, when they put too many pictures on one page it's a bit confusing for the clients, like on page 4 they ask some kind of questions "when you're with your girlfriend or something, when it's a private place or public place" you know those kinds of things, but they have four small pictures together. That is very confusing. There's too many. I think two pictures on one page is enough otherwise they look at something, they have an interest in that thing and they forget what you asked them or they mix it up with something else. So there is the confusion of the pictures (Clinician N).

Clinicians also expressed concern about the presence of line drawings and questioned whether photographs may be a better option to enable people with an intellectual disability to understand and relate to them better.

> I find sometimes that the pictures are not enough for some of the clients; because they are sort of small comic strip drawings. I don't know how to explain it, but it's pencil illustrated. Some of my clients need actual pictures so they trouble distinguishing some of it. Communication wise that's where it can confusing depending upon their level, especially when you're getting into the more moderate [intellectual disability]. They will have a bit of difficulty there with them understanding (Clinician P).

> A lot of clients don't understand [line drawings], which makes it difficult as well (Clinician Q).

Some clinicians expressed concern about the 'explicit' nature of the line drawings which again highlights the need for appropriate training to enable clinicians to administer sexual knowledge assessment tools and provide subsequent sexual health education.

> Once again I think there's some [staff] who will have trouble with it because it's got dirty pictures and some [staff] are really quite uncomfortable (Clinician K).
> I have some problems with the pictures, too. I think there's some times it's not clear …. I did worry about some of the… I don't know some of the pictures of the different sexual acts. I just wondered they're about now. Maybe they do need to be included. I mean they were just so confronting (Clinician V).

One apparent absence in the line drawings of all on the sexual knowledge assessment tools analyzed was the lack of representation of diversity in sexual orientation, age, body types and cultural groups (Table 3). While there are line drawings of people of different ages in the puberty section of the HRSKAAP-ID [11] and the ASK [12], there are no images which represent adults of different ages engaging in sexual acts. All of the people featured in the line drawings are slim and Caucasian. The ASK [12] has images of males engaging in same-sex sexual activity but does not represent sexual activities of people who identify as lesbian, bisexual nor does it represent people who identify as transgender.

Questions Clinicians found the questions in each of the topic areas do not cover the topic areas in enough depth. Clinicians also stated that they found the wording of the questions too complex for many people with intellectual disability.

> *Q. How well do you think the questions cover the topic area being assessed?*
> Without using additional resources, I don't think they cover it well. I think the biggest problem with my clients is understanding the questions and what I'm asking them. Unless I use other [resources] and other words, I won't get a valid real knowledge of what they know (Clinician Q).
> 'I think they're too complex, even though theoretically they've been adapted for people with an intellectual disability they must be way smarter than any people I've ever worked with. Some of the words I think, I don't even quite understand what this question is asking (Clinician M).

Stancliffe et al. [17] found that, compared to a standard assessment of loneliness with more complex question wording, the responsiveness of people with intellectual disability increased more than threefold when assessment questions with simplified wording were used. Stancliffe et al. evaluated question wording using Flesch Reading Ease readability scores which rate text on a 100-point scale. Higher the scores mean easier readability. These authors reported the readability of the standard assessment was 87.7 but 100 for the simplified assessment. Flesch readability is also a good proxy for ease of understanding when questions are read aloud to people with intellectual disability, as is typically the case when assessing sexual knowledge. To objectively examine the question difficulty of sexual knowledge assessment tools we also used Flesch readability scores. As an example, we tested the questions on masturbation in the HRSKAAP-ID [11] (readability = 77.7) and the ASK [12] (readability = 82.5) and found they were even more difficult than the standard assessment (intended for the general public) evaluated by Stancliffe et al. These

findings appear to confirm participants' comments about the overly complex wording of questions in sexual knowledge assessment tools, despite these tools being developed specifically for people with intellectual disability.

Level of Disability Clinicians reported that the ability to conduct assessments using the sexual knowledge assessments tools was significantly impacted upon by the level of intellectual disability experienced by the person being assessed and whether the person had other disabilities.

> With some people their communication issues might be such that the tool is pretty much useless (Clinician C).
>
> *Q. So what do you do if you can't use the assessment tool for a client, say if they've got a visual impairment or they've got a moderate to severe intellectual disability? What happens with those clients?*
>
> Well in one way you don't. I had a client, there was inappropriate sexual behaviour, he's blind and autistic and I looked everywhere to find an assessment for that and obviously because the ASK relies on pictures and I spoke to [other organizations] and they didn't have anything…So unfortunately there was no assessment tool at the time.
>
> *Q. So what happened?*
>
> They just don't get the assessment. I think in the area of education you can still get the education but I suppose you can't really get a gauge on how much they fully understand (Clinician L).

When people with intellectual disability were unable to engage in the sexual knowledge assessment process they were either not assessed or information about their sexual health was gathered by proxy from the people who supported them such as staff and family. Clinicians expressed concern that there was currently no formal process to do this objectively.

> *Q. What happens when the level of intellectual disability makes the assessment tools difficult to use with people?*
>
> It all comes down to the staff interpretations, well that's my experience anyway and that can be so broad and can change hugely from staff member to staff member. There needs to be a tool that has things for questions that don't require the staff opinion. Things like how many times a day does such and such touch his penis or when he's in the bathtub how many times, something like an observable, something that they can comment on rather than them saying "oh yeah, he's always grabbing himself" (Clinician K).

Problematic Behaviours Checklist in the ASK The problematic behaviours checklist featured in the ASK [12] was an issue for many clinicians and posed a risk of obtaining a score that was not a true representation of the person being assessed. This could potentially lead to people with intellectual disability being assessed as displaying problematic sexual behaviours and subsequently being labelled as deviant when this may not be the case. This labelling could lead to obvious negative consequences for a person with intellectual disability.

> I've moved away from the ASK. When I use that I thought it was fairly prescriptive and it had a whole lot of values…it's very much dependent upon, whether someone's a deviant or not, so if we go straight in and use the ASK it is assuming that they're deviant (Clinician D).

> The stuff on problematic sexuality at the back, I've used that once but because the language was so complex I found that the scores were not indicative. I didn't feel that I was getting a valid response from the person I was using it with, so I wasn't confident that any responses I was getting were valid and so I've not really used that (Clinician M).

Conclusion

This study builds upon previous research that has explored sexual knowledge assessment tools for people with intellectual disability. We interviewed clinicians—whose role is to support people with intellectual disability to achieve optimal sexual health—about their perceptions of the usefulness and usability of sexual knowledge assessment tools. We also conducted a content analysis of the two tools used by the clinicians interviewed as well as four other tools that are used internationally.

Based on our content analysis, we found that, with one exception, available sexual knowledge assessment tools for people with intellectual disability are essentially similar in structure and content. The ASK [12] is the only tool to contain a Problematic Socio-Sexual Behaviours Checklist. Overall, issues such as body parts and menstruation were generally addressed well, but topics such as sexual dysfunction and sexual aids received little or no coverage in any tool. We recommend that content on sexual dysfunctions, sexual aids, sexual pleasure and sexual pain needs to be added to these tools. With dates of publication between 1994 and 2006, it is unsurprising that no tool included content related to current information technology such as *sex and the internet* and *sexting*. These additional omissions reflect a clear need for the tools to be brought up to date.

With the exception of the HRSKAAP-ID [11], all of the assessment tools reviewed reported at least some data on their psychometric properties. However, no tool provided comprehensive psychometric data and none had extensive norming. Any redevelopment of the assessment tools needs to provide more comprehensive data on these issues.

It is well established that the sexual health of people with intellectual disability is viewed by many as low priority [5, 9]. It seems plausible that the limited development of sexual knowledge assessment tools identified in this paper may reflect the low priority of the sexual health of people with intellectual disability.

Clinicians found the assessment tools provided a useful foundation for them to assess the sexual knowledge of people with intellectual disability and they want such tools to support their work. However, clinicians expressed a need for more guidance on administering the tools and identified several shortcomings which impact on the usefulness and usability of the assessment tools.

Given the identified shortcomings of the current tools, there is scope for the development of new sexual knowledge assessment tools or refinement of the existing tools in terms of: (a) providing a more comprehensive administration guide, (b) including additional topics that incorporate other areas of sexual health important to people with intellectual disability that are not covered by the currently available tools, (c) simplifying the language to increase the accessibility of current tools, and (d) increasing the number and clarity of pictures in sexual knowledge assessment tools.

Limitations

Like many countries and jurisdictions, sexual health is not widely incorporated into disability service provision in NSW, Australia. As a result, there are few clinicians with experience and expertise in the sexual health of people with intellectual disabilities. This situation in turn led to the number of potential participants willing to be involved in the research being small. However, during participant recruitment efforts were made to ensure the diversity of participants so it is likely that as a group they are reasonably representative. A further issue was that 4 clinicians of the 23 interviewed had never used a sexual knowledge assessment tool. This fact no doubt limited their ability to comment on the usefulness and usability of these tools.

The two sexual knowledge assessment tools used by the participants were developed in Australia; therefore data surrounding their usefulness and usability may not be directly relevant in other countries. That said, the sexual assessment tools discussed are similar in content and questions to tools such as the SSKAAT-R [14], GSKQ [15] and the SKABAT [16] that may be used in other countries.

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Compliance with Ethical Standards

Conflict of interest None.

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