

‘Exploring the perspectives of young adults with developmental disabilities about sexuality and sexual health education’

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Abstract

Background: Sexuality is important in everyday lives; it contributes to a sense of self. Everyone has a right to access sexual experiences, form relationships, and obtain sexual health education. There is limited literature from the perspective of people with developmental disabilities about their sexuality and particularly how, or if, societal attitudes influence their sexuality and their opinions about sexual health education. The aim of this study was to explore the experiences of young adults with developmental disabilities about their sexuality, their perceptions about how their sexuality was viewed by the community, and about the sexual education that is required and how it should be delivered.

Method: A qualitative interpretative phenomenological approach using a purposive sample was used to explore the perspectives of young adults, aged between 18 and 32 years old with developmental disabilities, to explore their perspectives on their sexuality, societal attitudes, and access to sexual health education. Seven semi-structured interviews were conducted and analysed using an interpretative phenomenological approach.

Results: Five main themes were developed from the data: (1) sexuality is multidimensional and important, (2) the challenges and fear of expressing sexuality, (3) societal views need to change, (4) close support enables sexuality, and (5) sexual health education needs to be individualised.

Conclusion: Participants suggested that sexuality was important to them, and they had the same expectations about sexuality and relationships as many young adults. However, their autonomy and self-determination to set sexuality goals were constrained by societal attitudes. Supportive family and friends enabled opportunities, but they believed the knowledge and attitudes about disability, and about disability and sexuality, of community members, service providers, funders, and educators needed to change to enable increased opportunity to express their sexuality. Participants reported a need for individualised sexual health education provided by professionals with expertise.

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KEYWORDS

developmental, disabilities, education, intellectual, occupational therapy, sexual health, sexuality

1 | INTRODUCTION

Sexuality contributes to an individual's identity and is inclusive of sex, gender identity, sexual orientation, and reproduction and expressed through behaviours, thoughts, and relationships (Lynch & Fortune, 2019; World Health Organization, 2006). People with disabilities have the right to sexual and reproductive health and the right to marry and parenthood (The Convention on the Rights of Persons with Disabilities, 2006). Developmental disabilities describe a long-term disability that can impact intellectual functioning, physical functioning, or both, and the delay must occur before the age of 22 years (American Psychiatric Association, 2013; Schmidt et al., 2020). This study focusses upon young adults with either intellectual disabilities (IDs) or physical disabilities, not acquired disabilities. IDs are described in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) as general cognitive impairments that have an impact on adaptive functioning, and physical disabilities, including cerebral palsy, are described as a group of permanent disorders in the development of posture and movement, causing limitations in activities (Wiegerink et al., 2011). The term developmental disabilities is used in this study to encompass intellectual and physical disabilities that meet the definitions provided.

The goal of occupational therapy is to enable participation in occupations that provide a person meaning, value, and identity (Sakellariou & Algado, 2006). The Occupational Therapy Practice Framework: Domain and Process, 4th Edition (OTPF-4) (American Occupational Therapy Association, 2020) lists sexual activity as an activity of daily living. An individual's sexuality is a critical aspect of a fulfilling occupational life; it contributes to their identity, occupational desires, participation, and engagement (Lynch & Fortune, 2019).

People with developmental disabilities have the same sexual needs and desires as people without a disability (Borawska-Charko et al., 2016); however, their sexuality is often socially stigmatised, not acknowledged or supported (Eastgate, 2011; Esmail et al., 2010). Most studies that report on sexuality for people with developmental disabilities are from the perspectives of parents, educators, and health providers (Pebdani & Tashjian, 2021; Pownall et al., 2012; Tamas et al., 2019; Wilkenfeld & Ballan, 2011). As a result, there is limited research that

Key Points for Occupational Therapy

- Sexuality is an everyday occupation important to participation and self-identity.
- Occupational therapists can support self-determination and autonomy to participate in sexuality-related opportunities.
- Occupational therapists can provide education and advocate for young people with disabilities to access sexual expression opportunities.

explores sexuality and sexual rights from the perspective of people with disabilities (Esmail et al., 2010; Kelly et al., 2009; Sitter, 2015). Studies that have explored the perspectives of people with developmental disabilities have highlighted the physical and emotional challenges related to sexuality and noted that further research was required to determine a deeper understanding of the challenges they faced (Bernert & Ogletree, 2013; Wiegerink et al., 2011).

Positive attitudes toward sexuality and a desire for relationships have been expressed by people with ID (Gil-Llario et al., 2018; Retznik et al., 2021). Furthermore, sexual relationships and a sense of intimacy have been closely linked to the development of sexual identity in an Australian qualitative study of young people with cerebral palsy, as it nurtured a sense of being loved and accepted (Dune, 2012). People with ID have been reported to want intimate relationships and more than just a sexual relationship (Bathje et al., 2021; Sullivan et al., 2013). Being in a sexual and intimate relationship provided people with ID the assurance that they could be seen by society as 'normal' and respected as a sexual being (Bathje et al., 2021).

People with developmental disabilities have acknowledged the need for society to respect and provide opportunities for them to develop and express their sexual identity (Fitzgerald & Withers, 2011; Friedman et al., 2014; Turner & Crane, 2016; Wilkinson et al., 2015). However, people with developmental disabilities continue to experience barriers to their sexual rights, including the denial of their human agency, as well as overpowering infantilising by some parents/carers and workers that further limits their access to information and support that would enable their sexual identity (Di Giulio, 2003; Sitter, 2015). These

attitudes are also reflected in the wider community, creating barriers for those with disabilities to have the right to sexual autonomy (Rushbrooke et al., 2014). Furthermore, there is a common misconception of people with disabilities as asexual and in need of protection (Michielsen & Brockschmidt, 2021), as well as stigma, which restricts the development of sexual identity and deprive them of important knowledge that can keep them safe (Preston, 2013; Saxe & Flanagan, 2016; Treacy et al., 2018).

Sexual health education can help develop self-determination and for individuals to protect and understand themselves (Klein & Breck, 2010; Treacy et al., 2018). Young adults with developmental disabilities want to learn about relationships, safe sexual practices, and intimacy to support their sexuality (Frawley & Wilson, 2016; Ngyuen et al., 2018; Swango-Wilson, 2011). A lack of sex education, combined with limited support from educators, leads to non-comprehensive sexual education and missed opportunities to develop knowledge about sexuality, sexual health, and relationships (Frawley & Wilson, 2016; Michielsen & Brockschmidt, 2021; Ngyuen et al., 2018), which increases their risk of sexual exploitation (Treacy et al., 2018).

The gap in education is reported to be in part, due to stigma and a myriad of stereotypical beliefs about the sexuality of people with disability, including that they are asexual or hypersexual (Borawska-Charko et al., 2016; Esmail et al., 2010). There is a societal attitude that people with disabilities are not aware of their sexuality, not capable, or are disinterested in establishing intimate relationships, which leads to limited sex education opportunities and content that does not meet their need (Tamas et al., 2019). Family members have been reported to avoid the provision of sex education to people with disabilities for fear it will promote unwanted sexual activity (Tamas et al., 2019) and by professionals and caregivers who are elusive and uncomfortable in supporting sexual-related opportunities or providing explicit sex education (McConkey & Ryan, 2001; Travers et al., 2014). Furthermore, limited support and inaccessible sex education for people with disabilities are often linked with wide-ranging and negative implications, such as an increased chance of sexual assault and victimisation, as well as higher chances of being vulnerable to predation (Campbell et al., 2020; Hollomotz, 2011; Shakespeare, 2014).

The largely negative reporting of societal attitudes is mainly based on research with parents, caregivers and health providers, or broader community; little is known about the perspectives of young people with developmental disabilities about whether societal views do restrict their opportunities for sexual expression and access to appropriate education and the subsequent impact they think this has on their sexual expression, opportunity to form relationships, and sexual identity.

There is limited literature that investigates sexuality and sexual health education from the perspective of young people. This is important as knowing their perspective will promote access to appropriate services and education as highlighted by McDaniels and Fleming (2016) review of USA and similar Western societies, which found that individualised and specific sexual health education and services were lacking for young people with ID. Furthermore, young people with disabilities may be especially vulnerable to sexual ill-health (Michielsen & Brockschmidt, 2021); therefore, access to adequate sexual health education and support may mitigate this risk (Pecora et al., 2016).

The previous research provides insight into the sexual experiences of young adults with developmental disabilities (Bernert & Ogletree, 2013; Wiegerink et al., 2011). A study in Germany (Retznik et al., 2021) found that 42 participants with an ID had sexual experiences but had received limited support or lacked knowledge in how to best express their sexuality. This research aims to provide further information to support previous research; however, it also aims to address a key gap within the literature, which is what is the view of young adults with developmental disabilities regarding how they believe society views their sexuality and its importance to them. Addressing this gap within the literature will support young people with developmental disabilities to further construct their sexuality as a human right through upholding the notion that disabled people are free to choose how they express their sexuality (McGrath & Sakellariou, 2016).

Therefore, the aims of this study were to explore the experiences of young adults with developmental disabilities about their sexuality and the sexual health education they want and require, to support their sexuality, and to understand the perspectives of young adults with developmental disabilities about community attitudes toward their sexuality.

2 | METHODS

2.1 | Research design

A qualitative design, with an interpretative phenomenological approach, was used to explore the meanings that are subjectively attributed to a participant's experience and to describe how these meanings allow participants to make sense of their life experiences (Carpenter, 2017; Smith et al., 2009). This design is appropriate as it aims to provide detailed examinations of a personal lived experience (Liamputtong & Serry, 2017). This study received approval from the Human Research Ethics Committee, Australian Catholic University (2020-201EAP).

2.2 | Participant recruitment

Participants were young adults with a lifelong developmental disability, aged between 18 and 32, who were able to provide informed consent and communicate independently within a semi-structured interview. The age range of 18 to 34 years old for participants was used as there is currently limited literature reporting on their sexual health needs and wants, and a strong argument supports the need for and provision of sexual health education to young people (Michielsen & Brockschmidt, 2021). The term young adults commonly refer to people 18–24 years; however, people up to the age of 34 years have been classified as young adults (Australian Bureau of Statistics, 2013). Research involving adult populations commonly divides adulthood into three stages with up to 34 years defined as young adults (Franssen et al., 2020; Petry, 2002). A purposive sample was used which ensured that the participants were able to provide rich and in-depth information regarding the research topic (Carpenter, 2017).

Recruitment of participants occurred via an advertisement on the Occupational Therapy Australia website, the Occupational Therapy and Sexuality Special Interest Group, social media (e.g., Facebook), and through the research teams professional contacts. Participants for research were recruited directly and via health professionals through the researcher's professional contacts, who acted as a gatekeeper for the participant. Respondents were emailed a Participant Information Letter, which contained information regarding the research project in clear and easy to understand language, a consent form, and one researcher with lengthy experience working with people with developmental disabilities confirmed eligibility with a telephone call. Participants were informed that they could withdraw at any time, and written consent was obtained prior to participation in the study.

2.3 | Data collection

Individual, semi-structured interviews (60–120 minutes) were completed using Zoom© (Zoom Video Communications, 2023). The interview questions were piloted in a semi-structured interview, and no changes were made after completion. Rapport was established prior to each interview. Initially, the researcher engaged in general conversation with the participant to build rapport and to create a comfortable environment prior to commencing the semi-structured interview questions. An interview guide with open-ended questions was used to ensure consistency in questions between participants, while allowing elaboration and rich descriptions from their responses. The interview guide was informed by current literature relevant to the topic. All interviews were audio

recorded through Zoom© (Zoom Video Communications, 2023) cloud and were deleted from the software after the Zoom© recording was uploaded to Cloudstor.

2.4 | Data analysis

Interviews were transcribed verbatim, five by the first author and two by an external transcription company. Using Colaizzi's phenomenological framework (Carpenter, 2017), the first author, who has experience working with people with disabilities, used their experiences and client-centred and occupation-focused lens to complete the analysis, as positionality is important to report and aids in the interpretation that is part of the IPA analysis process. This involved reading and re-reading each interview and reviewing field notes to extract significant statements. The aim of this was to enter the world of the participant and make meaning from interpreting their stories from within and then across interview comparisons to develop key themes (Carpenter, 2017). The first author used their experience as a disability support worker and an occupational therapy honours student. The second and third authors, both experienced occupational therapists and used their experience and expertise in sexuality (CL) and in working with people with disabilities (AJ). The IPA process requires that researchers critically reflect to bracket their experiences to facilitate seeing the phenomena in new ways (Carpenter, 2017). All researchers read all transcripts and met to peer review the developing relationships between categories and to confirm the developed themes. To maintain dependability, an audit trail was maintained, and refinement of themes is shown in Figure 1. Credibility and confirmability were maintained by providing all participants an opportunity to member check. No changes were requested by the participants. Pseudonyms and minimal reporting of demographic information were used to maintain confidentiality.

3 | FINDINGS

Seven (four male and three female) young adults, two with intellectual and five with physical disabilities, lifelong not acquired, aged 18–32 years (mean age = 26.4 years and standard deviation = 4.37), who were able to provide informed consent and communicate independently in a semi-structured interview, participated in the study. See Table 1 for more participant details.

The participants reported on their perspectives of their sexuality, societal attitudes, and about sexual health education. Five themes were developed: (i) sexuality is multidimensional and important, (ii) the challenges and

Refinement of Themes

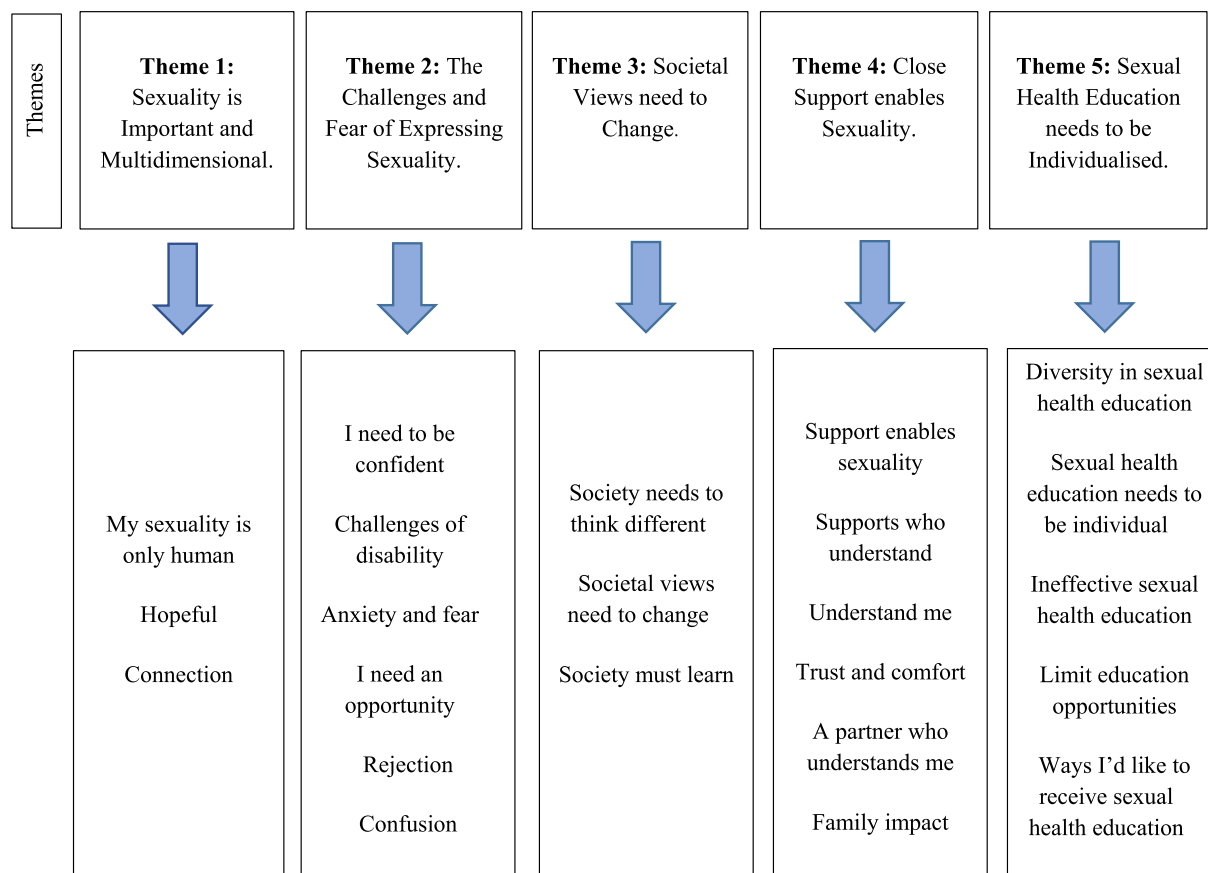


FIGURE 1 Refinement of themes.

TABLE 1 Participant characteristics.

Participant	Gender	Sexual orientation	Age (mean 26.4 SD 4.37)	Type of disability	Living arrangements
Sebastian	Male	Heterosexual	29	Cerebral palsy	N/A
Jackie	Female	Heterosexual	18	Intellectual disability	Family
Florence	Female	Heterosexual	26	Cerebral palsy	N/A
Sam	Male	Heterosexual	32	Cerebral palsy	Independent
Bailey	Male	Heterosexual	23	Intellectual disability	Family
Peter	Male	Heterosexual	27	Cerebral palsy	Family
Macey	Female	Heterosexual	30	Cerebral palsy	Independent

fear of expressing sexuality, (iii) societal views need to change, (iv) close supports enable sexuality, and (v) sexual health education needs to be individualised.

3.1 | Theme 1: Sexuality is multidimensional and important

Prior to discussing sexuality, participants were asked to share their thoughts and perspectives about what

sexuality meant to them. There was a general consensus that sexuality was innate, multifaceted, included doing of and the behaviour of sex itself, the way in which a person expresses who they are sexually, sexual orientation, gender, connection, and relationships with others.

Participants commented that they were no different to everyone else, but they believed that other people did not think they had the same rights, interests, and goals about their sexuality. Participants emphasised that disability did not mean that they 'don't have those feelings'

(Sebastian) and that disability did not define their right to finding a partner as 'it can't really stop me from going [out] with someone' (Jackie).

Personal views were shared by the participants; they, like everyone else, wanted to express their sexuality and have opportunities for personal and intimate relationships. Most participants hoped for and expressed their desire for an opportunity for a meaningful and lasting relationship. For example, Peter expressed that it 'it would be nice for me to have someone too'. Florence wanted 'to get married', and Bailey wanted to be 'with a family'.

The participants spoke from their heart and with a rights-based perspective to their belief in having the freedom to express their sexuality without judgement and to feel like a sexual being. Whether they had an ID or physical disability, the participants shared their beliefs that their hope for a long-term partner relied on them meeting someone who would understand and accept them for their disability. Participants shared their concerns about the likelihood of their hope being fulfilled, as Florence said, 'a lot of the time, we don't have the equal opportunity to get to know someone'.

The hope for love and connection was something most participants wanted, and as Florence said, 'we all want love, that's something that we need,' and as Macey highlighted, 'I think we're the ones [living with a disability] who seek that genuine connection ... I definitely think as human beings ... we yearn for that connection, all of us do'.

Although believing the opportunity to meet people and the desire for personal and intimate relationships was their right and most important to them, two participants reported their experiences with sex workers met aspects of physical needs but with different opinions about the benefits. For Sebastian, visiting a sex worker provided a sense of being 'fulfilled ... gratified, and so much more confident' (Sebastian), whereas for Peter, sexual experiences with a sex worker 'means nothing so ... I don't get those feelings [of love]', as it did not compare to being in a connected and genuine relationship.

3.2 | Theme 2: The challenges and fear of expressing sexuality

Accessing opportunity for sexual expression, meeting people, and forming relationships, either in person or online, posed a range of difficulties. Participants with physical disabilities highlighted online dating challenges such as navigating computers, interacting with dating applications, using their mobile phone to message others, and requiring support to catch transport or travel to places to meet new people. Participants also discussed that even when they did access online dating platforms,

finding someone to talk with them was challenging, as Sebastian disappointingly described:

I'm on two dating sites and I haven't got one match. And you know why? Because I'm in a wheelchair. I've been on those ones [dating sites] for five months now and I've only gotten one match. I try to make it an inviting profile, a profile that someone wants to get to know me or find out more about me, but it just doesn't work that way.

Several participants with a physical disability reported their opportunity was limited as soon as others saw their disability. Participants shared their sense of a disheartened feeling, when faced with people who responded adversely to seeing a physical disability, 'as soon as they see the wheelchair, they freak out' (Sebastian) and '[being] in a wheelchair ... people don't want that' (Peter).

Some participants spoke of unsuccessful past attempts at forming relationships and having limited opportunities to meet people because they had few social supports or did not know where to meet people, as Peter shared, 'one of the places I go ... no women go there ... the other place I go to, they're all old'. The difficulties participants faced were exacerbated by media as Florence described with disappointment, 'a lot of the time we don't see people with a disability getting married or having kids'.

The stigma and unsuccessful attempts had a significant impact on the participants' self-identity and sense of feeling like a sexual being. Participants discussed the rejection, anxiety, and disappointment that impacted their sense of who they were and their own worth, and as Bailey, who lives with an ID, shared, 'I think it would raise the fear of rejection, this person doesn't want to be with me because ... they think I'm weird. It would make it harder to approach people'.

Participants with a physical disability particularly felt challenged and shared needing to act confident, even when anxious, in the hope of encouraging others to approach them and see past their disability. Macey explained, 'I think it's a situation where the more confident you are and the more that you show that you're confident ... people kind of don't perceive you as having a disability in that case'.

3.3 | Theme 3: Societal views need to change

Participants discussed their belief that society needed to think differently about disability. Participants highlighted that people were quick to judge and label them and not

acknowledge their wants and needs as sexual beings, as Jackie shared, 'just because I have an ID, it doesn't mean that I won't find a man'.

Some participants highlighted that there was a societal view that people with any developmental disorders were not able to make informed decision regarding their right to, or their participation in, sexual opportunities. As Florence reported, 'unfortunately, in the dating world, a lot of my friends with CP have had mixed reactions from people because some people don't actually see someone with a disability as like going on dates ... getting married, having children'. Participants thought the concerns came from questions about safety, sometimes out of genuine concern, but some attitudes just came from a misunderstanding and misconception about disability and sexuality. From the participants perspective they were seen as 'less of a person' (Macey) and from Sebastian, 'when I tell people that I ... have a sexuality, they're quite surprised and shocked and they're like are you sure you know what you're doing, is it safe'.

Most of the participants agreed that society viewed disability as an inconvenience or something that was too challenging to deal with and that these attitudes had a negative impact on seeing themselves as having a right to sexual opportunity. All the participants strongly believed that societal views needed to change, that greater community awareness and education was needed, and that people needed a deeper understanding of disability and sexuality, as shared by Sam:

I think there's a lack of information of the benefit to adapting to people with disability. You've just been told by people without disabilities to accept people with disabilities because they're human beings, that's the rationale for people without disability. That would be a big step in accepting people with disability and being comfortable talking about topics such as sexuality.

3.4 | Theme 4: Close supports enable sexuality

Participants reported that their sexuality was enabled when they felt empowered by close friends and family who were supportive and willing to discuss their sexual wants and needs but also felt inhibited when their wants and needs were misunderstood. The importance of a supportive network and someone to talk to was described by Sebastian, 'it just depends on how strong your support network is around you, and whether they encourage or hinder you in pursuit of your goals'.

For most participants, their supportive network was close and understanding family members who enabled opportunities, as Bailey described, 'my family is good with it [sexuality] ... they're just supportive'. When close family members were supportive, participants reported being comfortable in talking about their sexuality and trusting them, but other participants reported the opposite. Sam shared his thoughts, 'they [parents] can be too protective and too smothering when it comes to allowing them to explore themselves [sexually]'.

Some participants reported support coming from close friends who 'know me the most' (Jackie) and who also knew their goals relating to their sexuality. Participants described this support as 'an open-minded friend' (Sam), a support who would empathise with them, as well as a friend who has 'no judgement' (Sebastian) and that they tended to push away friends who were not understanding. This attitude was what participants also reported as wanting in a partner, as Florence passionately shared, 'if you really love a person, even if they're not really like you, how different they are. You will still love them; you will still want to be around them ... they make you feel safe'.

Participants highlighted that close supports that enabled their sexuality were vital as they were often misunderstood by people who did not know them well. This resulted in a lack of understanding about their capabilities and their sexuality-related wants and needs, as Macey described with dejection, 'people see us as a disabled person ... everyone has their judgements. Not a lot of people have come from a place of understanding.' It was not just individual attitude that limited opportunity but also the societal view as commented by participants wanting to use the National Disability Insurance Scheme (NDIS) to enable them to have choice and control over their own goals. Sebastian reported that visits with a sex worker were not funded because they were not regarded as essential and 'seen as unreasonable and unnecessary'.

3.5 | Theme 5: Sexual health education needs to be individualised

When asked about sex education, all except one participant highlighted that the only sex education they had received was in primary and secondary school, which for some participants was more than 15 years ago, and it only focussed on anatomical and physiological aspects of sexuality. Topics were mainly about sexually transmitted diseases, condom use, and anatomical differences, whereas participants wanted content about emotions and roles in intercourse, masturbation, relationships, and relationship coaching, as well as supports that were

specific to people with physical disabilities, for example, equipment to support their sexuality.

Participants all reported that past education was not inclusive, as described by Sebastian as being 'tailored around the able person' and by Sam who commented with a sense of disbelief that disability was ignored, 'every information about sexual education has to do with people without disabilities ... I haven't seen anything in media that is sexual health education for people with disabilities'. Sebastian explained this with a sense of disappointment:

The majority of it [sex education] was just theory and pracs that the class was doing I couldn't do. And that made me lose interest further, I was like how the hell am I going to put a condom on a banana. Like with how my hands work and how my disability works, it just didn't work.

Some participants discussed that their past sex education experiences resulted in them losing interest in learning more about their sexuality from a younger age, as highlighted by Florence, 'I didn't really go to those things [sex education] because I wasn't really interested, I found it really boring'. Participants also shared their perspective of being affected by the attitudes that had kept them 'sheltered' by sex educators and teachers that "definitely didn't teach it as open and honestly" (Macey).

Participants described getting most information they needed now from supportive friends, family, and the internet, but if other education was available, they had a preference that it would be individualised, private, and trust needed to be developed if they were to discuss their sexuality, as Florence commented, 'I think because it's kind of personal [sex education], I think it's better to do it one on one'. Some participants also wanted content that was coaching and relationship focused.

Participants noted that education needed to be taught visually, through role play or using other approaches that were more than reading or talking about sex, as discussed by Jackie in her words, 'I think talking about it [sex education] would be the hardest' and Bailey, 'reading [about sex education], is where I struggle the most'.

4 | DISCUSSION

This study provided a rich description of the experiences of the young adults with developmental disabilities about their sexuality and their sex education needs. As such, it provided important information about their perceptions about whether they believed societal attitudes, including

those of carers, service providers, and broader community, had a negative impact on their opportunities for sexual expression and to have intimate relationships and on the sex education available.

The young adults all described sexuality as a human need and important and that they had the same wants and needs for sexual opportunity and relationships as anyone else. This contrasted with the prevailing societal attitude that still views people with disabilities, as being asexual or having less sexual need, reported in a recent systematic review (Pebdani & Tashjian, 2021). However, despite current participation in online dating and having family and friends who supported their sexuality, the young adults all reported rejection, fear about being accepted, that they were hopeful but not confident that they would have opportunities to express their sexuality with others or form intimate relationships, and this further impacted their sense of self and their sexual identity. This finding is consistent with the experiences of 42 young people with mild to moderate ID (Retznik et al., 2021) and has implications for the education that is provided to all community members to reduce the stigma and normalise the experiences and expectations of people with developmental disabilities.

The young adults reported that the limitations were in part due to their disabilities, for example, difficulty using computer, and other mobile technology to access online dating sites, sometimes from needing other resources such as transport and access to suitable social environments. More often, it was due to limited support and resources that they received/accessed from service providers or family members and negative attitudes about their rights to sexual expression. Young adults with a physical disability believed they were seen as wheelchair users rather than sexual beings, which has been reported previously in relation to 'visible' disabilities (Esmail et al., 2010). The young adults with ID reported misheld views that they could not make decisions that would keep them safe in sexual experiences, which was consistent with previous findings (Pebdani & Tashjian, 2021). The findings emphasise the need for parents/carers, service providers, and educators to have a rights-based attitude and an understanding of the need for autonomy and self-determination for young adults with developmental disabilities and their sexuality.

The young adults reported that societal views negatively impacted their rights to sexual expression; opportunities to form relationships; their identity and their access to education, reflecting the widely held misconceptions about their rights, abilities, and needs, previously reported from the perspectives of parent/carers; the general population, educators; or other service providers

(Pownall et al., 2012; Tamas et al., 2019; Wilkenfeld & Ballan, 2011).

The clear message from the participants was that sex education was taught mostly in school, was focused on anatomy and physiology, and it needed to change; it was viewed as not inclusive, not helping peers see they had the same rights, and it was not practical or adequate, as previously reported (Ngyuen et al., 2018; Schmidt et al., 2020; Swango-Wilson, 2011). Inadequate sex education was linked to a lack of expertise about disability specific needs, and limited honesty and transparency, sometimes due to family and service providers trying to shelter and protect them, also reported in earlier studies (Michielsen & Brockschmidt, 2021; Pownall et al., 2012). Community attitudes that people with disabilities did not have the right to or did not need or want sex education were given as some reasons for inadequate sex education and this are also consistent with literature that reports on the perspective of educators and families of those with disabilities (Gürol et al., 2014; Healy et al., 2009). These findings highlight the need for parents/carers, service providers, educators, and school peers to have a deeper understanding of disability and sexuality, to see that sex education was important for these populations, and to negate the loss of identity and right to sexual expression that is common for people with disabilities who do not receive adequate and supportive sex education (Campbell, 2017; Campbell et al., 2020).

These findings suggest that for change to occur, education about disability and about sexuality and disability needs to be a community focus and provided by trained professionals. This education also needed to be extended to some service providers and funding bodies such as the National Disability Insurance Agency, as some participants reported not having choice and control over their personal goals and the right to self-determination because funding to address sexuality issues, such as visiting a sex worker, was regarded as 'not reasonable or essential'.

The young adults reported that they currently get most information they need online or through talking with friends. They also wanted funding and access to professional services that could provide relationship coaching, teaching about initiating and developing relationships, a better understanding of the physical and emotional roles of intercourse, navigating sexual experiences, as well as support to navigate online dating. They reported support needed to be individualised and should include role play, adapted practical activities, and videos rather than textbook-based education, which is consistent with previous findings regarding sex education for people with disabilities (Box & Shawe, 2014). Occupational therapists and other professionals are well positioned to provide education, address access, and participation issues

and to advocate for the rights of people with disabilities (McGrath & Sakellariou, 2016), to allow for choice and control, self-determination, and autonomy over sexuality-related decisions and their personal goals.

4.1 | Limitations

The intent of an interpretative phenomenological study is to not generalise but to understand the lived experiences of the participants (Carpenter, 2017; Smith et al., 2009). This small study provided valuable insights into the perspectives of young adults with disabilities who are sometimes excluded from opportunity to be engaged in research. However, saturation was not reached, so caution is required in transferring the findings and further studies with each disability group is recommended.

4.2 | Implications

This study highlighted the importance of understanding the lived experience of young adults with developmental disabilities about their sexuality and sex education needs. Education for peers of young adults with developmental disabilities is also required to help navigate challenges such as online dating, setting up dating profiles, and having relationships. There is also a need to address community attitudes that restrict the ability of young adults with developmental disabilities to express their sexuality, with occupational therapists, and other health professionals and educators well placed to support and advocate for positive changes in the young peoples' sexuality and in community education.

Implications for further research include understanding young adults with developmental disabilities perspective about societal education and awareness required to change society attitudes, as well as larger studies that explore more deeply, the differences in the lived experiences of young adults with developmental disabilities about their sexuality and sex education needs.

5 | CONCLUSION

The importance of sexuality to young adults with developmental disabilities was paramount, but the young adults believed community members needed education about disability and about disability and sexuality, if they were to have equal opportunities for sexual expression, intimate relationships, and education. This study also strongly indicated the need for individualised and diverse sex education that enabled opportunity and kept people safe.

AUTHOR CONTRIBUTIONS

The first author collected and analysed the data and drafted the manuscript. All authors contributed to conceptualising the study, data analysis, and reviewing the current version.

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DISCLOSURE OF INTEREST

The authors report no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

All research procedures reported in this thesis were approved by the Human Research Ethics Committee Australian Catholic University (2020-201EAP).

CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

CONSENT FOR PUBLICATION

Informed consent was obtained from all individual participants included in the study.

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