

‘As Normal as Possible’: Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood

Abstract

During transition to adulthood, emerging adulthood is characterized by continuous identity negotiations [1]. However, for young people with intellectual disabilities (ID) the ID identity may overshadow the development of sexual identity [2, 3]. This study conducted an in-depth exploration of four young people and four of their carers’ experiences of the development of sexual identity alongside the ID identity. Interviews were analysed using Interpretative Phenomenological Analysis (IPA). Young people struggled for an ‘*as normal as possible*’ adult identity, and to develop sexual identity as a ‘*normal*’ identity, in the context of the overshadowing ID identity. Despite believing they should be enabled to develop sexual identity as part of their transition to adulthood, young people faced many obstacles, including stigma related to their ID. Carers described their challenges in proactively supporting sexual identity education and exploration, due to concerns about risk. Equality and protection need not be either/or priorities; however, there remains need for considerable change in UK practice and policy if the principles of rights, independence, choice and inclusion [4, 5] are to be met in relation to sexual identity development in people with ID transitioning to adulthood.

Keywords: Intellectual Disability, Transition to Adulthood, Sexual Identity, Sexuality, Identity Development, Carers, UK.

Introduction

Becoming an adult is a complex transition for young people with intellectual disabilities (ID). People with ID (also referred to as learning disabilities, or intellectual developmental disorders) by definition will have impairments in their intellectual ability which impact on their adaptive functioning and ability to manage independent living, which occur during the developmental period with a lasting impact on functioning [6]. In a society where adulthood is perceived as reaching independence [7], young people with ID find themselves treated as children for longer due to their continuing support needs, perceived vulnerability [8], and delay or inability to achieve 'adult' goals, such as independent housing [9]. A transition also occurs for carers [10], who play a crucial role in supporting young people through the transition to adulthood [11].

A key task of transition is the development of coherent adult identities [12], with contradictions in developing identities leading to conflict in thinking about the self [13, 14]. Identity is interactional, with parents, peers and society contributing to young adults' identity construction and negotiation [15]. During transition, emerging adulthood is characterized by continuous identity negotiations, where experiences may be variously interpreted using personal, social and relational identities [1].

The ID identity is highly stigmatized [16], and becomes incorporated into young people's self identity at an emotional level through day-to-day interactions and relationships, through their awareness of the power others exert over their lives [17]. Despite this, there has been remarkably little research into the effect of being

categorized as having ID on an individual's ability to develop coherent self-identities, although the ID identity has been theorized to be so powerful that it becomes a person's primary identity, overriding sexual identity [18].

Historically, attitudes towards the sexuality of people with ID were so negative that segregated institutionalization and sterilization were imposed to prevent people with ID reproducing [19]. Whilst some recent studies suggest moderately liberal attitudes about the sexuality of people with ID from those who support them [20, 21], opportunities for expressing sexuality remain limited and controlled by others. Overall, people with ID continue to struggle to be seen as sexual beings, with the right to an informed and fulfilling sex-life [22, 23]. Carers remain cautious about discussing sexuality with people with ID, fearing it may encourage sexual behaviour or intrude on privacy [24, 25]. Conservative carer attitudes have been found to directly influence the sexual attitudes and experiences of people with ID, and conflict with people with ID's sexual wishes and right to ordinary sexual lives [5, 26, 27]. There remain particular barriers to Lesbian, Gay and Bisexual (LGB) people with ID receiving support to develop positive sexual identities and relationships [24, 28, 29].

Few studies have investigated people with ID's experiences of sexual identity development during transition to adulthood. Young peoples' sexual exploration has been shown to be restricted by limited privacy, high dependency on carers, and carers' ambivalence between enabling sexual development and protecting young people from pregnancy or abuse [30]. Contextual restrictions, such as access to education and restrictions on social opportunities, may also prevent the development of sexual expression and knowledge, and consequently sexual identity [31]. The 'childlike' ID

identity has been found to act as a barrier to parents addressing their offspring's sexuality [32]. Young people and their parents' embarrassment around discussing sexuality is likely to be more salient for young people with ID, because they have less access to other forms of information and support, and may lead them to develop negative attitudes toward their own sexuality [32].

Despite the crucial role carers play in negotiating and constructing adult identities alongside young people with ID, no existing research has conducted an integrated exploration of young people and their own carers' experiences. This research aimed to investigate the development of sexual identity during transition into adulthood for young people with ID from the perspectives of young people with ID and their carers, to provide an enriched, triangulated understanding of this process [33], and shed light on the nature of the care relationship and its role in sexual identity development during transition to adulthood [34]. Interpretative Phenomenological Analysis (IPA) was judged the most appropriate method to explore individuals' internal negotiations of meaning and privilege participants' subjective experiences of sexual identity, which may contribute towards a change in social discourses where people with ID have historically been denied a voice [19, 35].

Method

The study was reviewed and approved by both the appropriate University and National Health Service (NHS) ethics committees prior to commencement. All participants gave consent to participate and for publication of the research in a publication such as this, however pseudonyms are used throughout to protect

anonymity. Where quotes included are particularly sensitive, pseudonyms are not used to further anonymize information.

Semi structured interviews were conducted with four people with ID and four of their carers accessing a London service for people with ID. A purposeful opportunity sampling method was used. The sample included people with ID who had verbal competence to participate in interviews and who freely gave informed consent to participate. Each young person also selected a carer to participate. This sample of eight met the recommendations of Smith et al. [33] for IPA studies, which assert the value of in-depth, micro analyses of a small number of participants' experiences. The demographic variables of the young people are displayed in Table 1, and the demographic variables of the carers are displayed in Table 2.

Table 1 Demographic Variables for Young People

Demographic Variable	<i>n</i>
Gender	
Male	2
Female	2
Ethnicity	
White British	3
Black African	1
Living situation	
Family Home	2
Group Residential Home	2
Age range	19-22 years

Table 2 Demographic Variables for Carers

Demographic Variable	<i>n</i>
Gender	
Male	2
Female	2
Ethnicity	
White British	2
Black African	2
Caring Role	
Parents	2
Residential Support Workers	2
Age range	28-50 years

An interview schedule developed in collaboration with service users was used to set a loose agenda, anticipate sensitive issues and frame questions openly and accessibly. Questions which the young people were asked included: ‘What do you think about having a girlfriend or a boyfriend?’, and ‘What is important for you in the future?’ Questions which their carers were asked included: ‘Can you tell me what it has been like to experience [young person]’s sexual development?’, and ‘What do you want for [young person]’s future?’

Data analysis was an inductive and iterative process based on the common IPA processes and principles outlined by Smith and colleagues [33]. This included detailed descriptive and interpretative coding of transcripts, the identification of emergent themes within each transcript, and conceptually organizing master themes by

identifying patterns and connections between the group of young people, their carers, and the groups as a whole. The framework of master themes was used to compare and contrast the emergence and meaning of themes for each member of a dyad [34]. Quality standards for qualitative research were followed (Elliot et al., 1999; Yardley, 2000), and credibility checks undertaken to strengthen the validity of the analyses.

Results

The master themes that emerged from the data were ‘the struggle for an ‘*as normal as possible*’ adult identity’; and ‘the struggle for sexual identity as a ‘*normal*’ adult identity’. The development of adult sexual identity can be viewed as a battle within the wider war against the ID identity as a defining ‘child-like’ identity, as illustrated in Figure 1. The carers’ position within this struggle for ‘as normal as possible’ identities shifted between alliance and opposition to the young people in the context of complex societal attitudes and demands.

Fig. 1 Pictorial representation of master themes

The struggle for an ‘*as normal as possible*’ adult identity

All participants emphasized young people’s struggle to develop an ‘*as normal as possible*’ identity while continuing to find themselves defined by their ID identity. During transition to adulthood, this struggle seemed to focus on achieving a ‘*normal*’ adult identity, as a means of moving away from the ID identity perceived to be infantilizing.

Negotiating an ‘as normal as possible’ identity...

Negotiating an ‘*as normal as possible*’ identity represented a key aspect of identity development for the young people with ID. Strategies were used to create distance between the young person and their ID by aligning them as closely as possible with a ‘*normal*’ identity, while balancing the need to acknowledge their difference. This was encapsulated by one of the carers, Naomi:

‘I just see him as normal as possible.’ (Naomi, carer)

The balancing act between the ID identity and an ‘*as normal as possible*’ identity appeared to be a central concern for one of the young people, Charis. By minimizing her disability in comparison to others, she seemed to negotiate an identity as close to ‘*normal*’ and as distant from other people with ID as possible without denying her ID identity outright:

'I just got a mild one, so...I haven't got that much like other people got.'

(Charis)

She appeared to evade owning the ID identity even at a linguistic level in this extract, avoiding any use of the ID label lest it become associated more strongly with herself. Her carer noted the apparent success of her strategies on how she is perceived by others:

'I don't think she gets judged on [her ID] too much, because she puts herself across as a normal person.' (Darren, carer)

By minimizing her ID and distancing herself from others with ID, Charis appeared to successfully negotiate an '*as normal as possible*' identity, which functioned to protect her from the judgement of others.

...But being defined by the ID identity

Despite their efforts to create distance between the young people and the ID identity, young people and their carers described how it continued to define the young people. While young people seemed to struggle against this, their carers appeared to take on a role of accepting and endowing the ID identity. This conflict is outlined in the following extracts from Hannah and her carer, Susan:

'The nurse tell my mum who I am first, and what my face comes up with.

Cause see my face, I born like this.' (Hannah)

'Cause she's special needs, you kind of take control of her, answering everything for her.' (Susan, carer)

From birth, Hannah appears to have been stripped of control over her self-identity. Instead, her disability meant her permanent resignation of control over 'who I am' to professionals and carers. She appears used to her appearance being taken as an indication of an overshadowing ID identity, overriding any alternative identity she attempted to establish. The ID identity appeared to dominate Susan's understanding of Hannah, leading her to assume inability based on Hannah's 'special needs' identity. Susan's apparent view of ID as Hannah's primary, defining identity may indeed make it difficult for Hannah to develop alternative identities.

A further way the ID identity defined the young people was through the impact of stigma:

'I have special needs, it's sometimes very hard because people look at you differently, and that's what makes you angry inside.' (Gary)

Gary emphasized the negative effect the stigmatizing views of others had on his identity through the emotional impact of being seen as different. He appears to have found himself defined by others' perceptions of his difference, leaving him less able to shape alternative identities and thus seemingly isolated, devalued and 'angry inside'. Another young person, Michael, appeared trapped between identifying with

and distancing himself from the ID label, and his assertion seems laden with contradiction and doubt:

'[I] think I have one disability because when you say learning disability you're gonna like get yourself at risk like [...] But I'm not one of them but.' (Michael)

While young people seemed to struggle against being defined by their ID, their carers appeared to accept and reinforce ID as young people's primary identity:

'At first he didn't understand that he got disability, so you got to try to see from him, does he know himself, what is he.' (Naomi, carer)

Naomi moves from a description of disability as something the young person, Michael, has, to something he is. ID appears an all-encompassing identity, to the extent that if he does not understand or accept this label, he cannot 'know himself'.

The struggle to escape the ID identity through achieving adult identity

The transition to adulthood appeared to present a window of opportunity during which young people struggled to break free from the 'infantilizing' ID identity by attempting to achieve a highly valued adult identity:

'People treat me more like an adult, when I was a kid people used to treat me like shit.' (Charis)

'Basically, there has been a transition in us, in myself, just leaving it with her, and I've seen her change...' (Darren, carer)

For Charis, her adult status seemed to allow her to escape people treating her 'like shit', but also seemed beyond her control, attributed to her by others. Darren indicated that his own transition towards allowing Charis greater power by 'leaving it with her' enabled her to develop an adult identity. However, her ID identity seemed to continue to overshadow the adult identity by keeping her under others' control:

'I feel like I'm a bit of a baby...But it's our, it's my safety, so.' (Charis)

The continued 'protective' power that the ID identity gave carers over Charis seemed to leave her feeling infantilized. She appeared to have internalized the message that she needs protection, leaving her seemingly powerless to fight to be treated 'more like an adult'.

The struggle for sexual identity as a 'normal' adult identity

All participants expressed the idea that developing sexuality was a normal part of transition to adulthood for people with ID:

'I don't care what anyone else says. I'm just a normal person that wants a girlfriend, like any other teenager in the world, any other grown man would want one.' (Gary)

Gary seems to be actively fighting against the idea that he is not a ‘normal’ sexual adult. By aligning himself with ‘any other teenager in the world’, then further emphasizing his adulthood by shifting the alignment to ‘any other grown man’, he emphasizes that his sexual identity deserves to be acknowledged and respected, perhaps despite an expectation that it will not be. It seems possible such an expectation may have been formed on the basis of negative responses to his sexuality, which appeared to be supported in his carer’s account:

‘If he has sexuality.’ (Jude, carer)

Jude appeared to voice the view that as a young person with ID, Gary may be a non-sexual being. It seems likely that young people whose carers hold ambivalent positions towards their sexuality may struggle to receive the support they need to develop a positive adult sexual identity. It appeared that no matter how hard the young people fought, their ID identity continually marked them out to others as not ‘*normal*’, and therefore not sexual. The right to a sexual identity which would define young people as ‘*normal*’ adults seemed out of reach for all of the young people.

The ID identity creates multiple barriers to developing sexual identity

Although all participants expressed the idea that developing sexuality was a normal part of transition to adulthood, they outlined the many barriers that the ID identity posed to sexual identity development during transition to adulthood. These included: carers’ views of young people as non-sexual or ‘child-like’; the struggle to receive (or in the case of carers, provide) accessible sex education and support; mutual

embarrassment about discussing sexuality; and carers inhibiting sexual exploration in order to manage risk.

The barrier of embarrassment discussing sex is of particular importance for young people with ID, whose social isolation means carers' positions regarding their sexuality have greater salience compared to non-disabled peers. This is outlined by Hannah and her carer Susan:

'Cause the sex thing's like, embarrassing, I don't want [Susan] to know.'

(Hannah)

'If if, if it needed talk about, yeah. I would do. I think if she had a boyfriend I think I would then have a discussion with her about it, but I'm sure she'd be 'oh [Susan]!'' (Susan, carer)

For both, the thought of discussing sex with each other appeared embarrassing and uncomfortable, forming a vicious cycle, with each individual's anticipation of the other's embarrassment forming a barrier to bringing sex up. Hannah may have developed the idea that mentioning her sexuality is embarrassing through interactions with others, including her carer. Susan's repetition of 'If if, if' may indicate her reluctance to bring up the subject of sex with Hannah. She seems to be waiting until she 'needs' to address Hannah's sexuality, perhaps when this poses a problem or potential risk, rather than facilitating sexual development as part of Hannah's emerging adult identity.

All of the carers acknowledged the barrier their involvement could pose to young people's sexual identity development, but explained how concerns about managing risk and being held responsible for the safeguarding of young people often conflicted with facilitating sexual exploration. Darren highlighted this in how he would respond if Charis had a partner:

*'Personally I would, alarm, alarm would come and say we need to know more about this person, because we're here to safeguard people like Charis'.
(Darren, carer)*

For Darren, his purpose as a carer seems to be safeguarding Charis from harm. Rather than viewing her forming relationships and exploring her sexual identity as a normal part of transition to adulthood, he appears to perceive this as an immediate and urgent threat. 'I would alarm, alarm' creates the image of Darren himself becoming a red, ringing alarm, and it appears difficult for Darren to balance the potential threat with Charis's potential gain of a partner. It seems likely that Darren's heavy risk management focus could jeopardize a relationship's natural development over time, at potentially great cost to Charis. In turn, Charis expresses a sense of being labelled as vulnerable, and consequently given less freedom:

'They want our safety. If I'm delayed a bit longer I have to call them to make sure I'm, why I'm a bit late or something.' (Charis)

Double disadvantage: The ID identity restricts the development of LGB sexual identities

Stigma around people with ID as sexual beings appeared to combine with stigma around LGB sexuality to further restrict sexual identity, posing a double disadvantage. This was reflected in carer Jude's apparent difficulty in considering the possibility that as a young person with ID, Gary may be gay:

'Researcher: What would you think if Gary said that he wanted to have a boyfriend?

Jude: He can't say, he can't say he can't say before they're ready that I want to have a girlfriend.'

Jude's triple repetition of 'he can't say' indicates the strength of his feeling that Gary cannot say he wants a gay relationship, but also gives the impression of an internal struggle to explain why this is so. He seems to resolve this by changing the question to apply to heterosexual relationships, as if the idea of a young person with ID embodying sexuality beyond a heterosexual model is so dissonant with his beliefs that it cannot be processed and must be converted back towards the heterosexual 'norm'. For Gary, the combined stigma of those around him towards LGB people with ID seemed to have a huge effect on his sexual identity development:

'I do think I was gay at school, 'cause I liked guys, I didn't like girls mostly. Well, then I decided not to be gay, cause I got bullied. I didn't want to be anything I knew I'd get bullied badly for.' (Gary)

It seems he decided to change his sexual identity to reflect an ‘acceptable’ norm set by others in an attempt to protect himself from further victimization. His assertion that ‘I didn’t want to be anything I knew I’d get bullied badly for’ seemed to resonate with his feelings towards his ID identity, as if his identity already presented more ‘difference’ than he could manage among his peers. The double disadvantage faced by LGB young people with ID was also apparent in the lack of appropriate sex and relationship education and support to enable sexual exploration they received.

Young person: ‘[the gay bar is] open too late...I need someone who can work that long.’

Researcher: ‘Would that be difficult?’

Young person: ‘Maybe.’

Due to the ID, this young person is reliant on carers to enable access to the people and places necessary to explore and develop an LGB sexual identity, and to a sense of belonging to this group.

Discussion

This research utilized the qualitative IPA approach to provide a rich, in-depth understanding of how young people with ID understand and negotiate sexual identity as they transition to adulthood, from the perspectives of young people and their carers. The results outline the struggles young people and their carers experience in negotiating an ‘*as normal as possible*’ adult identity, which includes an ‘*as normal as possible*’ adult sexual identity, in the face of the overshadowing ID identity.

Young people with ID strove to align themselves with a coherent '*as normal as possible*' adult identity using strategies including minimization and denial. This extends adult findings by indicating young people attempted to resolve cognitive dissonance resulting from incoherent externally assigned and internally experienced developing identities by negotiating these internally and according to context, as predicted by the 'kaleidoscope' theory of identity [1]. Carers seemed caught between presenting young people as '*normal*' and subscribing to societal ideas around their vulnerability and deficiency. This supports social constructionist theories of identity development as continually renegotiated through interaction with others [36], and highlighting the powerful impact carers' attitudes and expectations may have on young adults' ability to construct '*normal*' identities [15].

Despite their efforts to distance themselves from the ID identity, young people described how it continued to define them. Their physical differences and support needs seemed to inescapably mark them as 'different'. Though young people worked to minimize the impact of stigma, their definition by others' perception of their difference made it seemingly impossible to achieve a coveted '*normal*' adult identity [37]. The results provide a novel examination of this struggle between young people, who appeared to fight against the defining ID identity, and their own carers, who seemed caught between accepting and rejecting the young people's developing adult identity in the context of their continuing '*child-like*' ID identity.

Young people and their carers appeared to view the transition to adulthood as a window of opportunity through which they could break free from the '*infantilizing*'

ID identity by achieving a highly valued adult identity. This placed young people under pressure to meet the 'adult' goals of people without ID in order to achieve an adult identity, regardless of their ongoing support needs and decreased likelihood of achieving 'adult' goals such as independence compared to non-disabled peers [8, 9]. Such expectations may set young people up to fail in their goal of achieving a conditional 'adult' identity, leaving them trapped in an 'almost-adult' state. It is well established that transition to adulthood can be particularly distressing for young people with ID; this study suggests that this may be impacted by pressure to 'grow out' of the ID identity, combined with the lack of power and control young people hold over this longed-for escape [38].

The achievement of an adult identity, coveted as an escape from the 'child-like', stigmatized ID identity, seemed conditional on developing a sexual identity which the overshadowing ID identity denied young people. This extends previous research supporting Burns' [3] theory; the ID identity overshadows sexual identity not just for adults [18, 27, 39, 40] but also for young people at the age of transition. Young people appeared to actively fight against their sexual identity being overshadowed by fighting against restrictions enforced by carers, extending existing research with adults [27, 40].

The ID identity appeared to create many barriers to developing a 'normal' sexual identity. Carers seemed caught between accepting sexual identity development as '*normal*', and subscribing to stigmatizing views of young people with ID as non-sexual, extending findings with adult women to apply to women and men during transition to adulthood [40].

Carers' involvement in facilitating or restricting sexual exploration was a particular difficulty for young people with ID, corroborating previous research conducted with groups of young people [31] and adult men [41]. Sexual education and support seemed influenced not by the young person's needs, but by their carer's embarrassment, expertise, and beliefs about how their sexuality should develop. The results corroborate several possible explanations for this, including: carers' lack of expertise and support [31, 32, 42, 42]; little opportunity for sexual expression due to limited available social opportunities, restrictive shift patterns and transport restrictions [31, 43]; and carer ambivalence between allowing opportunities for sexual development and risk protection [28, 30]. It should be acknowledged that carers are often caught in the tension between empowering young people with ID and the concern that young people and adults with disabilities are at greater risk of abuse [44, 45]. However, the risk-averse nature of carers and services, and the low priority they afford to people with ID's sexuality, form a barrier to people with ID fulfilling their right to sexual lives through restricting sexual identity development during transition to adulthood.

The ID identity also appeared to place a 'double disadvantage' upon the development of LGB sexual identities. Hetero-normative attitudes and stigma were apparent in carers' failure to acknowledge or address the possibility that young people with ID may not be heterosexual, and the lack of LGB sex and relationship education and support they provided, extending previous research with adults [24, 46] and corroborating previous research with young people [30, 47]. Some young people seemed to have internalized others' negative attitudes towards LGB people with ID,

which seemed to link with difficulty in developing positive LGB sexual identities, extending recent research with adult women with ID [48]. Sadly, the stigmatizing attitudes apparent in research conducted nearly a decade ago remained prevalent.

The current research is limited. The IPA approach facilitated an in-depth exploration of young people and their carers' experiences [49]. However, a complex issue was the need to balance the open questions necessary to allow participants to relate their own experiences, with the need to support participants with ID to understand and answer questions by using concrete concepts, examples, and fixed choice questions. A compromise was reached by using broad questions followed by successive prompts where necessary; however, this balance may not have always been met. IPA research aims to obtain a relatively homogeneous sample, which may be divided to obtain multiple perspectives on a single phenomenon [33]. The use of young person-carer dyads allowed an exploration of the fundamentally important carer relationship [10] and the role this played in sexual identity negotiations during transition to adulthood [34], allowing a richer narrative of the participants' experiences to be explored. The purposeful opportunity sampling method allowed for detailed, in-depth analyses, but meant the results cannot be seen as applicable to the wider population [33]. The analyses could have been strengthened by longer term involvement with the participants to facilitate trust and rapport.

There are several avenues for the present findings to be extended. This research left several important voices unheard, including those of less able participants, and of fathers and siblings of young people with ID, whose experiences remain important to explore. Furthermore, quantitative methodologies may be utilized to broaden this in-

depth exploration by investigating whether the themes derived apply to a broader range of young people and carers.

Sadly, the ID identity's power to overshadow sexual identity development appears to have changed little for young people growing up in the UK since the publication of the government White Papers *Valuing People* and *Valuing People Now* [4, 5], indicating there remains need for considerable change in practice and policy if the principles of rights, independence, choice and inclusion are to be met in relation to sexual identity development in people with ID as they transition to adulthood. There is also concern that within the current political climate of austerity and the weakening of the welfare state, the *Valuing People* policies and principles may be sidelined [50, 51]. Change is necessary in several areas, including:

- Professionals, carers and families taking an active role in bringing up issues of sexuality to break down the barriers posed by taboo and embarrassment
- Increasing the scope of and access to sex and relationships education
- Service and carer prioritization of facilitating sexual exploration by removing barriers such as curfews and restrictive shift patterns
- Training for all professionals, carers and families in discussing and supporting sexuality, and addressing hetero-normative biases
- The introduction of clear policy guidance to support carers to facilitate sexual exploration while managing risk.

Overall, a shift is needed away from a paternalistic, risk averse approach to sexual identity development, towards facilitation and collaboration with young people. Equality and protection do not have to be either/or priorities if they are approached as

an integrated process to enhance young people with ID's sexual identity development. These difficulties can be overcome by trusting that young people with ID are able to make choices about what they want, and providing proactive support to help them overcome the many hurdles they face in developing positive sexual identities as part of their transition to adulthood.

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