Article

Telling Disabled and Autistic Sexuality Stories: Reflecting upon the Current Research Landscape and Possible Future Developments

Alex Toft

School of Social Sciences, Nottingham Trent University, Nottingham NG1 5LT, UK; alex.toft@ntu.ac.uk

Abstract: Developments in the study of sexuality in the lives of disabled people have been relatively slow, as the spectre of a medicalised model continues to dominate most debates and invalidate any form of sexual identity. The social model of disability has enabled the amplification of voices that have been previously silenced; however, progress has stalled. Within autism studies, however, the rise of neurodiversity studies coupled with intersectionality, has presented an opportunity to explore sexualities in terms of difference rather than deficiency, therefore bypassing deficit models which have dominated any study of non-heterosexual lives. Such deficit models have focussed upon discovering what it is about autism that leads autistic people to think they are non-heterosexual, often resulting in a lack of support for young LGBT+ people as sexuality is dismissed as a result of autism. Reflecting upon findings from my own ongoing work alongside emerging social research, this article explores important developments and potential future directions. This will highlight the progress made and the barriers remaining. Using a sociological approach and a framework inspired by Plummer, which focusses upon the importance of sexual stories, the article will show that much needs to be done. The diversity of goals and multiplicity of stories means that disabled and autistic sexuality stories have not been accepted into the public consciousness.

Keywords: sexuality; gender; disability; autism; sexual stories

1. Introduction

When exploring sexuality in the lives of disabled or autistic people, the first barrier encountered revolves around perceptions about the capacity to possess a sexuality identity. Indeed, before any exploration of sexuality, research has to make the case that sexuality is an essential part of everyone’s lives and that disabled or autistic people are not inherently non-sexual. As with non-disabled and allistic (those who are not autistic) people, sexuality is varied, but disabled or autistic people are subject to closer scrutiny and questioning due to perceptions about capacity and capability. Research that has taken an equality and human rights perspective shows that sexuality is an important aspect of identity for disabled and autistic people [1–3], but this is often dismissed and not supported. Much of the research has given undue focus to sexual behaviour in disabled or autistic lives that is seen as problematic (the literature is vast, but a few examples are: [4–6]). In autism research, there has been an almost obsessive focus upon trying to discover what it is about autism that makes autistic people think they are LGBT+. This echoes much of the research surrounding autism in general which continues to strive to categorise and understand what are perceived as the deficiencies of autism, as opposed to accepting difference as a result of neurodivergence.

This article aims to examine the social research landscape around work exploring the lived experiences of disabled or autistic persons who identify as LGBT+. This echoes much of the research surrounding autism in general which continues to strive to categorise and understand what are perceived as the deficiencies of autism, as opposed to accepting difference as a result of neurodivergence.

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often counterproductive. Such debates, as well as the decision to separate disability and autism, will be considered in the next section.

Specifically, the article will do two main things which will give the reader insight into the progress made but also the barriers which remain. First, there will be a commentary and overview of work in this area. This will give an overall picture of what has been compiled so far, and the focus of the research to date. Although this is not an area of extensive research, the aim is not to provide a systematic overview (other reviews do this much better, such as [7]), the focus here is a guided commentary paying particular attention to the biggest developments and my own research in this area. There is no claim that all the literature is included here. The contribution of this article is in the analysis of the research landscape alongside presentation of my research. Second, the article will briefly explore frameworks that have emerged or been applied to this area of research. It is not the goal to explore all the theoretical frameworks for conducting research and understanding disability or autism, but rather to focus upon those which may be useful when exploring disabled or autistic LGBT+ lives.

Following this, there will be analysis of what needs to happen for progress to occur. Again, the focus is not to explore all barriers, but to offer a commentary on what my research suggests. The focus here will be upon practical challenges but also making sure that the lives and the stories of autistic or disabled people are central to progressing the narrative. It is not the goal to create an overly complex theoretical model which is useful entirely to academics, but rather an accessible and realistic approach which is useful for all. The work of Plummer [8] will be central to this as it focusses upon the importance of the everyday and the power of stories.

The article begins with an important discussion on key concepts and the language used in the article before moving to the sections described above. Although most of the concepts and the research discussed is widely applicable, my work takes place in the UK, and this is reflected throughout.

2. Notes on Language and Key Concepts

This article has two key points of clarification with regards to its focus: the decision to separate out autism and disability and the focus upon sexualities rather than sexuality and gender identity. These decisions will be explored here. Such observations are based upon my previous work [9–15] and my understanding of the research landscape.

The decision to separate disability from autism has been made as a reaction to the research landscape. Whilst the majority of research on disability and sexuality includes autism, research on autism and sexuality never includes disability. Disability research in this regard takes a broader approach and tends to be inclusive of anything that is considered an impairment. Research which explores sexuality and disability may include disability in its widest sense (including autism), or it may be more specific. Autism, as a specific type of neurodivergence, has been separated, and many would not see it as fitting with what is commonly understood as disability. As it is a highly contested concept, researchers have been keen to concentrate solely upon autism where possible. Additionally, it is important to recognise that research on autism and sexuality/gender is the area of most research growth. As a result, this article will explore sexuality alongside disability and/or autism. It is clear that this approach is not inclusive as there are other neurodivergences that could have been included which fit within a disability umbrella (e.g., ADHD). This is important for future researchers to address. However, this approach has been guided by my own research which has explored disability and autism, either as a collective or individually.

This article is primarily concerned with research that focusses upon sexuality. However, it is clear that in practice much of the research includes sexuality and gender, often under acronyms such as LGBT+. Such research is concerned with non-heterosexuality and marginalised gender identities and explores the challenges and barriers faced for such individuals. What is not focussed upon here is research specifically examining gender and
disability/autism. Although the main themes will be touched upon as they relate to LGBT+ research, this is simply because this is beyond the scope of this article.

As with my previous work, the key terms used here are the preferences of my research participants. LGBT+ is used when discussing sexualities and gender identities that are non-normative [14]. Furthermore, identity-first language is used throughout (e.g., disabled person and autistic person). This is important for the young people in my research as ‘person with autism’, for example, is considered as being offensive and labels them as ill [9]. This is in line with neurodiversity studies [16] which are informed by a social model of disability [17] and highlights how society excludes and disables people with impairments.

3. Methods

This article is reflective commentary on existing literature, frameworks and methods that have been used by researchers who have been exploring autism, disability and LGBT+ lives, consisting of my analysis of existing research in relation to my own work. This has been my area of research for around the past decade and has resulted in a wide variety of publications [9–15], all of which contained narrative reviews. This article uses this work, but in order to write such a commentary, an additional review was conducted which broadly aimed to capture all research using keywords derived from the disability, autism and LGBT+ across social sciences databases (PsychINFO, Scopus, Google Scholar). No date restrictions were placed upon the searches due to the paucity of literature available.

In order to make sense of the literature and to explore why barriers remain, the article foregrounds the stories told by the participants in my research. To do this, the article uses Plummer’s work on sexual stories [8] to understand why disabled and autistic sexuality stories have not been accepted into public consciousness and how this can be remedied.

4. Social Research on Disabled and Autistic LGBT+ Lives

4.1. Research Focus

Although research on sexuality/gender in the lives of autistic people has started to grow as a result of the positive developments in neurodiversity studies, the sexualities of disabled and autistic people is rarely seen as a research priority. Within disability studies, there have been theoretical developments, but this has not resulted in research which has explored LGBT+ lived experiences. Disability is traditionally an under-researched area with sexuality being an often-ignored intersection [18,19]. Autism research is largely concerned with trying to understand autism and its causation (the literature is vast, but a few useful reviews are: [20–22]) rather than autistic people’s lives [23] or even listening to autistic people [24,25]. This is, of course, is accentuated when looking at specific groups within the population, as noted by Wilson et al. [26] who highlighted a total absence of research exploring sexuality in the lives of intellectually disabled children, young people, and the elderly. With regards to autism, Lewis et al. [27] reported in their literature review that there were only three qualitative studies in this research area and that previous research had tended to focus upon gender and health concerns.

4.2. Misconceptions and Misperceptions

The lack of research interest in this area reflects misconceptions about sexuality in the lives of disabled people. As Dinwoodie et al. [28] have highlighted, public perception remains that disabled people are not sexual beings. Research in this area has often failed disabled people as it has excluded their voices, although there are a number of scholars working to ensure that disabled voices are present in research [13,29,30]. Throughout the history of disability research, there is a clear pattern of conducting research without the involvement of disabled or autistic people [31]. As a result, the research agenda has not served disabled people’s best interests with research of questionable value. Research comparing the behaviours of disabled and non-disabled LGBT+ people [32] has only served to ‘other’ disabled people and highlight how such lives are incompatible. This has been pushed further by some researchers who have looked to regulate others’ sexualities by
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ascribing labels of weirdness or abnormality [33]. This has been particularly emphasised with the focus upon trying to show a link between autism and asexuality. Such research starts with the hypothesis that because autistic people are viewed as having certain social/emotional deficiencies, their sexualities will reflect this [34–36]. Such an approach is not an accurate reflection of asexuality, which is a sexual identity chosen by people to reflect their intimate lives (see Cuthbert [37] for a more nuanced understanding).

My research has shown how most misunderstandings of sexuality in disabled or autistic people’s lives are related to issues of capacity/capability and whether LGBT+ identities are legitimate for disabled people [14]. My research is full of stories of young people who were not believed and whose experiences were dismissed. This reflects the continued denial of disabled people as experts in their own lives. The pattern of infantilisation and desexualisation is clear. This has serious implications for young people who cannot live as they desire, but also in terms of the education and support they receive. Relationship and sex education is often withdrawn as it is not seen as a requirement, and young disabled people are left with no access to formal support. There is also a tendency to delegitimise LGBT+ identities by linking them to disability or autism. In my research, a respondent called Tom (pseudonym) discussed how his parents thought being bisexual was a result of him ‘being unwell’. This was an inaccurate representation of autism, which also questioned the legitimacy of his bisexuality [11].

4.3. Connections between Disability, Autism and LGBT+ Identities

Such connections and attempted linkages between disability or autism and sexuality can be problematic because they attempt to compare movements which are disparate and unique. However, the majority of autism research exploring sexuality is concerned with these connections because there is a belief that understanding why more autistic people are LGBT+ produces greater insight into autism. This project is ultimately flawed because it continues the assertion that LGBT+ identities and lives are inferior. As Corker [38] insightfully highlighted, the parallels between disability and non-heterosexuality (Corker was writing about lesbianism) reflect in fact, that both are considered inferior.

Societal understandings and public perceptions also highlight a number of parallels and potential alliances, many relating to the continued medicalisation of both. My research with disabled bisexual young people highlighted a number of parallels between their histories [11]. The goal of this was not to show that the experiences were the same; rather it was to show how the prevailing medicalisation has resulted in similar challenges. Specifically, I noted that there were three parallels that related to:

1. The tendency to need to prove both;
2. The underlying narratives of fixing or curing;
3. Erasure or invalidation due to misunderstanding. (Adapted from [11])

The participants demonstrated how bisexuality has to be proven in order for it to be seen as a valid identity. To be bisexual, you are required to have relationships with a variety of genders, preferably simultaneously. It was not until this occurred that bisexuality could be confirmed. Issues of visibility also feature in disabled people’s lives. Only visible disabilities were considered valid, and a number of the participants noted how they were often not seen as being autistic enough if they were not enacting well-known aspects of autism; even if they are not part of their lives (such as difficulties holding eye contact). Narratives of fixing and curing permeate both. Bisexuality was seen as not making one’s mind up, whereas disability has a complex relationship with finding cures. My research is full of stories of young people who experienced others telling them not to worry about their sexuality because it would pass or that advances in medical science would fix their disability. Connected to this, the parallels and shared histories show how both are invalidated and erased because they are positioned as ‘avoidable’ [11].

The emergence of neurodiversity studies and its adaptation to explore LGBT+ lives has further questioned research which attempts to understand autism through sexuality [16]. Such scholars have opened the door to exploration of what autism can tell us about sexuality.
and other social constructs. This re-alignment is more fruitful because it allows autism to be explored as difference rather than deficit, which is a more accurate reflection of autistic lives. Jackson-Perry [39] imagined the potential impact that autistic peoples’ ‘failure to conform to imagine sexual and gender realities’ (p. 226) could have upon preconceived ideas of autism, but importantly upon sexuality and gender. This supposition re-aligns autism as being something that can teach the wider population about sexuality. In my collaborative exploratory research with young people, we found that sexuality and gender are fragile constructs that autism challenges [9]. This aligns with research into gender, as autistic people often do not feel the need to ‘do’ gendered roles [40].

The response to this should not be to focus upon what is missing or abnormal in autism, and such an approach is not fruitful. This highlights how autism is a type of neurodivergence, where difference is the key and not the deficiency. Although research has shown that autistic people are more likely to be a sexual minority [41,42], this has not resulted in an exploration of these sexualities as it should have. What this suggests is that autistic people do not follow established social constructs or norms (either purposefully or otherwise). Sexuality, as a socially constructed category, behaves no differently here, as autistic people do not fit with such models. The importance of this relates to how it demonstrates the man-made nature of LGBT+ identities, which are mainly to do with power and control over people. Unfortunately, because of misunderstandings around autism, such exploration is likely to be limited.

The probable first reference to viewing existing models of sexuality/gender as being ableist or not fitting with the lives of those who are neurodivergent comes from the work of Jack [43]. Jack highlighted how autistic voices show that understandings of sexuality and gender should be seen as neurotypical models, as autism ‘denaturalises’ such categories. Others have attempted to claim this perspective by creating language to explain the connection between autism and LGBT+ identities. This is most notably through the labels of autisexual/autigender [44–46] and neuroqueer [47]. Both are largely concerned with trying to untangle the linkages and connections at play. Neuroqueer recognises the intertwining and interaction of neurodivergence with gender. Autisexual/autigender are used to show the inseparability of autism and LGBT+ identities, where autism is visualised as a filter for how the world is experienced [46].

My own research exploring the relationship between autism and LGBT+ identities has highlighted the usefulness of the labels autisexual/autigender [9]. Participants talked about the connection between the two in terms of how autism is a filter for experience of sexuality/gender, but this was presented as neurodivergence and inevitable, rather than as a negative presentation of deficient sexuality/gender. What the stories of the participants suggest is that the search for what is missing or deficient from autistic people’s sexualities is not the correct approach. This medicalised view of autism does not reflect the lived experiences of autistic people. Although autistic people are more likely to be LGBT+ [41,42], this tells us more about autistic people’s relationship with social norms and how fragile constructions such as sexuality are. Autism shows that these created categories are open to disruption.

4.4. Identity

There are many challenges and barriers that disabled LGBT+ people face in terms of living everyday whilst identifying as LGBT+ and being disabled. The experiences of young people for example, highlight the perpetuation of the ‘phase’: the idea that LGBT+ identities are fleeting identifications for disabled people. This can result in young people being dismissed and not taken seriously. This leads to isolation and feelings of misunderstanding [27,48]. A high proportion of the literature from the US has focussed upon the aspect of community, stressing the importance of a supportive community for affirming identity [48–51]. This approach seems to be in-line with the work of Plummer [8] in that it places a strong emphasis upon the importance of community in affirming identity and a sense of self. However, this appears to be an over-simplification for those who are
disabled or autistic and LGBT+. Community itself has been challenged as a meaningful or even a realistic construct, as it excludes and isolates those who do not fit within its strict remit [52]. Recent studies which evangelise the role of community need to be cautious of the blanket claim that community fixes many issues, as community in this regard can be damaging and counterproductive.

The call for a more nuanced approach is also evident in research focusing upon decisions to vocalise sexuality/gender or to ‘come out’. Although established narratives of coming out stress that it is non-negotiable and the only way to live authentically, in real life this may not always be desirable, beneficial or safe [28,53,54]. Young disabled LGBT+ persons must be strategic in how they approach telling others about their LGBT+ identities. This ‘coming out’ is best viewed in terms of a life-long career but also as a strategic identity management tool. Using the work of Orne [55] as the theoretical framing, I argued that the act of coming out is not simple [15]. It is not necessarily something that must be done to live a better life. There are reasons to come out (or not), but these are strategic and need to consider issues such as safety and personal well-being. My participants came out (or did not) for a number of reasons:

4. To educate others—to show that you can be LGBT+ and disabled and to educate others about how this worked in their lives;
5. To support others—if other people were to raise LGBT+ issues in public, they would come out to help others;
6. To protect themselves—strategic ‘outness’ was vital, and this was acerbated due to disability;
7. To protect others—perhaps surprisingly, young people considered how their coming out would potentially affect others and did not want to put others in a difficult position;
8. To gain access to community—although communities were often seen as unwelcoming towards disabled people, a sense of belonging or access to support was often highly sought after. (Adapted from Toft [15])

4.5. Education

Although in the UK, guidance into relationship and sex education (RSE) has recently been updated to include same-sex relationships [56], much confusion remains over what can be taught [57]. What is clear is that schools are not sites which challenge heteronormativity [58,59] and therefore re-enforce intolerance towards LGBT+ people. Not feeling comfortable discussing LGBT+ issues has a history in disability research, most notably with Abbott and Howarth’s [60] important research which showed how professionals struggled to support LGBT+ clients. In schools, this has resulted in disabled pupils being removed from lessons [60,61]. If disabled people do receive RSE, it is most often focussed upon issues of reproduction and contraception [62]. This deficit in education has also been noted by young autistic LGBT+ persons who called for more education on relationships and consent [12]. This has been noted by Herrick and Datti [49] who called for educators to be sensitive to the intricacies of autistic relationships and to mindful of social and emotional needs.

Misconceptions about disabled people not needing RSE are often linked to the belief that exposure and education equate to promotion [63,64]. However, what is clear is that RSE is an effective tool in preventing abuse [65], which disabled people are more likely to experience [66]. In fact, the over-protection by withdrawing RSE means that young disabled people do not have safe and supportive environments to explore sexual relationships, which could in turn result in unhealthy relationships [67].

My research has also shown the importance of the hidden curriculum, particularly in terms of role models in education settings. Relationship and sexual education has been largely unsuccessful as it does not include disabled lives. A more radical approach than continuing to revise formal curriculums has been to attempt to change the whole school ethos and create an environment of LGBT+ inclusion [68]. This can also be achieved through the encouragement of role models or more specifically, disabled LGBT+ mentors [12,69].
Knowledgeable and visible role models within schools have a positive effect, although being visible within schools is often difficult [70].

5. Frameworks and Methods for Investigating Disabled or Autistic LGBT+ Lives

5.1. Early Research and the Social Model

It would be an accurate generalisation to state that the majority of research exploring the lived experiences of disabled LGBT+ persons has been exploratory. For an emerging area of research, this is understandable, and such exploratory research has done much to contribute to an increased understanding and rejection of outmoded stereotypes. Medicalised or essentialist perspectives still hold a great deal of power, particularly in terms of autism research which unashamedly frames autism as something to be cured. This has been accentuated by charities, such as Autism Speaks, Inc. (the largest autism charity in the US), who articulate this belief.

Although it is a relatively small field of research, there have been a number of methodologies which have been adapted as useful frameworks for the study of sexuality in the lives of disabled/autistic people. These have ranged from continuations or applications of existing models to complex new frameworks. Not all frameworks are represented. For example, there is no critical realist examination, and only parts of some other methodologies have been adapted for use (e.g., critical disability theory and intimate citizenship).

It is clear that there currently is no consensus on the most fruitful approach, and most appear to be heralded by lone voices. This section explores some of these frameworks. While there is not space to explore these complicated approaches in intricate detail, the goal is to provide a commentary on how these have been used in relation to the lives of disabled/autistic LGBT+ persons.

The history of research exploring disability or autism in relation to sexuality often does not make pleasant reading. Much of this is the result of the researchers approach to disability or autism. Indeed, research into disability in general does not have a positive history in terms of inclusion or prioritising the needs of disabled people [31]. In terms of sexuality, the focus has been upon exploring sexuality and sexual behaviour from a detached position with little involvement from disabled people themselves. The rise of the social model, however, gave research a framework to work against the dismissal of sexuality in the lives of disabled people or as medical phenomena to be investigated (this application of the social model can be seen in Shakespeare [71] for example). The move away from medicalisation towards working to understanding how society disables people has meant that the emphasis and victimisation of disabled people has shifted. During this period, research contributed to better understanding of the challenges and negotiations that LGBT+ disabled had to face in their lives but also the strategies employed for dealing with this (e.g., coming out [72], community life [73], and disability rights [71]).

5.2. Beyond the Social Model

Although, as noted by Oliver [17], the goal of the social model was not to create a research framework, the ethos of the social model has clearly been an important stepping-stone for the exploration of LGBT+ lives. It is clear, however, that the social model is limited when exploring lived experiences, as it tends to undersell the power of human agency [74]. The social model cannot plot the resistance of disabled people to homophobia, for example, because it positions disabled people as being at the mercy of society’s ableism. Recently, scholars have become critical about the social model, and for some, the focus on rights-based research became overbearing and restrictive [75]. As a result, critical disability studies emerged as an attempt to move away from such materialist approaches [76]. Although rather unwieldy in its potential application in research, the openness to draw upon other fields has been useful for researchers. Most notably here is intimate citizenship [77,78] which explores the barriers preventing disabled people exercising their intimate lives. Some important non-LGBT+ research has adopted this approach [79,80]. Application of these approaches to non-heterosexual lives has taken some adaptation. MacRuer [81] was
most likely the first to do this by exploring how able-bodiedness and heterosexuality are intertwined. This approach, often labelled as ‘queering’ has been applied to research, perhaps most notably in the work of Chappell [82]. Chappell worked to highlight the fluidity of sexuality/gender and note how both disability and sexuality have been trapped by essentialist constructs of able-bodiedness and heteronormativity.

5.3. Emerging Frameworks

The alignment of queer theory and disability studies is perhaps most notably presented by MacRuer [18] who developed their ideas further with the creation of Crip Theory. Crip Theory is a complex framework aiming to explore the way in which neoliberal capitalism has led to the formation of sexual and embodied identities. In short, it attempts to uncover how able-bodiedness and heterosexuality have become dominant, whilst disability and queerness are constrained. McRuer’s theorisation is replete with examples from popular culture, but the applicability to research is only just emerging with examples of its application in education [83], disability justice [84], authenticity [85] and masculinity [86], to provide a few examples.

There are also new emerging fields which may be important in future research. Sexual fields theory [87], for example, has been applied to the exploration of disabled people’s intimate lives [88]. Although rather complex a difficult to grasp, sexual fields develop Bourdieu’s [89] theories of social fields based on class and social standing. Santinele Martino [90] convincingly makes the case that due to issues of ‘surveillance, infantilisation, and control, people with intellectual disabilities have to claim and convert spaces not typically meant to be sexual fields, such as day programmes, group homes and other settings, in the pursuit of intimacy and love (p. 1231)’. How this translates to LGBT+ lives will be interesting to uncover in the future.

As previously noted, there appears to be little cohesion or agreement amongst scholars with regards to which framework is most fruitful. There are many islands working separately without a strategic approach. Whilst such theorisation is interesting, the service that it is providing to disabled people’s lives is debatable. There is clearly a trend in both disability and sexuality studies to attempt to create new models without respecting or acknowledging previous work and building upon it.

The majority of articles about disability, autism and LGBT+ lives conclude by calling for a more intersectional approach. This was noted back in 2013 by Goodley [76] and continues to be stated [90]. This repetition suggests that this is an area of research priority that has not been substantially addressed as yet. My research has taken a strategic essentialist approach to this and focussed specifically upon certain intersections, namely: age/youth, disability, autism and LGBT+. This was purposeful and as a result of the lack of research in this area. I felt that it was beneficial to explore how these intersections interact. Then, this could be developed further in the future. As a result, I have been able to explore aspects, such as why LGBT+ identities are denied to disabled and autistic young people [14], RSE needs [12], coming out stories [15] and the connections between LGBT+ and disability and autism [9,11].

Neurodiversity studies provides a framework that moves the emphasis away from seeing autistic sexuality as a problem with autism towards seeing sexuality as ableist and not inclusive of autistic lives. Put simply, the emphasis has shifted towards working to understand how autism challenges concepts, such as sexuality, rather than searching for deficits in autism. The work of Rosqvist [91] has laid the foundation for this, and it would appear that this, coupled with an intersectional approach, has the potential to create important and beneficial work for autistic people [92].

My own approach has been to try to incorporate intersectional thinking with a storied approach, that I loosely called Intersectional Storytelling. This was created to describe what I was attempting to do when collecting stories but also how I was attempting to analyse the stories. It was inspired by Plummer’s work on sexual stories [8] and important developments in intersectionality [93–95] to try and ensure the stories shared touch upon
the multifaceted nature of experience, guided by the participants’ stories. It is clear that this approach is not a framework, as it does not suggest new ways of understanding disability/sexuality beyond the stories that are told. However, this proved useful in ensuring the findings were led by the young people’s lived experiences.

Research has thankfully moved this further with co-produced and collaborative approaches which have begun to emerge in the study of intimate lives and disability [79,96]. Although there are difficulties and negotiations in power relationships and what is meant by ‘giving voice’ (e.g., the reliance on a researcher to give voice) [97], research needs to be guided by whose lives it impacts upon. This has been specifically noted in terms of autistic lives where collaborative work has shown to reduce ableism [98]. My own collaborative work conducted alongside the Young Disabled LGBT+ Researchers Group has been shown through a project (the Under the Double Rainbow Project) developed in its entirety in a co-produced fashion (from conception to dissemination) to explore the lived experiences of young people who are autistic and LGBT+ [9]. Whilst such collaboration involved careful negotiation and planning, particularly around timescales and ensuring that workloads were appropriate, it was a positive and important step forward.

6. Moving Forward

6.1. Research Progress

In their recent chapter, Santinele Martino and Campbell [90] propose four key areas that need to be addressed in research exploring disability and intimacy:

1. Research needs to include ‘all’ disabled people, not just those who can easily participate in research;
2. There needs to be an intersectional focus;
3. There needs to be a focus on pleasure (as opposed to focussing solely upon challenges);
4. All research needs to be collaborative and co-produced. (Adapted from [90])

These are powerful and accurate messages. The point of reproducing them here is not to critique them but to show how little has changed in the past 30 years (at least in research). We know, for example, that the work of Ann Craft in 1987 [99] highlighted misconceptions about disability and the ‘forever child’, meaning that research was not thought of being worthwhile with many disabled people. The medicalisation of disability and autism has meant that anything positive about disabled or autistic sexuality is not seen as a valid area of research. In terms of co-production and collaboration, this message has been repeated since at least the early 1990s. Charlton [100] reported that they first heard the phrase ‘nothing about us, without us’ in 1993 from Michael Masutha and William Rowland who were two leaders of Disabled People South Africa. The phrase has since been accepted into common parlance and it is used without citation. However, what is clear is that this has not been achieved, although there are a good proportion of researchers working with these values.

6.2. Sexual Stories

This final section, then, asks why things have not changed significantly: why disabled or autistic LGBT+ stories have not been revised and what are the barriers? To do this, I will invoke the work of Plummer [8] to focus upon how the formation of new sexual stories that could move narratives forward in this area. This approach gives a good justification for the importance of sexual stories, the challenges of getting stories accepted in the public consciousness, and how to encourage such stories to be adopted. However, where appropriate, I will highlight the limitations of this approach and how it needs to be adapted.

People tell sexual stories to assemble a sense of self and identity. Sexual stories lay down routes to a coherent past, mark off boundaries and contrasts in the present and provide both a channel and a shelter for the future. If they do their work well, sexual stories will give us a sense of our histories-partly of our own life
and where we’ve come from, but no less a sense of a collective past and shared memories. They will provide a cause, a sequence, a history. [8] (p. 172)

Plummer’s groundbreaking work on sexual stories presented an account of how telling stories is vital for matters of personal identity. Put simply, it was proposed that we tell stories to make sense of who we are and where we belong. Certain powerful stories that we tell proliferate and seep into the public consciousness, in turn becoming accepted narratives or truths for the phenomena in question. In ‘Telling Sexual Stories’ Plummer examines how certain stories, such as gay coming out stories, become these accepted narratives, whereas others remain isolated and floating, having failed to make a cultural impact. There are, according to Plummer, stories which are still awaiting their time. I assert that the stories of disabled or autistic LGBT+ people fall into this category.

Certainly, there are stories—important stories at that—which remain largely hidden from sight. Much of the sexual can still not be said, and there are stories that may well be awaiting their time. [8] (p. 114)

As previously noted, the suggestions for future research tend to repeat the same few suggestions, and little has changed. What is missing is an analysis of why progress has been slow and what needs to be done to change this. I argue that Plummer’s framework can give us this. Disabled or autistic sexual stories have not aligned with current accepted narratives which has made them difficult to gain acceptance. The issue does not lie with stories themselves, but in the cultural landscape in which they reside and how the stories are constructed. In this final section I will do three things:

1. Examine what the current stories about disabled or autistic LGBT+ lives look like;
2. Explore how new stories can be adopted into public consciousness and the stages for achieving this;
3. Demonstrate how disabled or autistic LGBT+ people are empowering themselves and how this can be supported by others.

6.3. Current Disabled or Autistic Sexuality Stories

There are a number of reasons why disabled and autistic sexuality stories have not been accepted as valid narratives. These revolve around a series of misconceptions and prevailing assumptions relating to: capacity/capability, LGBT+ identities as a symptom of impairment, medicalisation of disability and deficiency narratives concerning autism. Put simply, the existing stories are negatively framed stories of oppression. The intersectional nature of the identities means that alignment with existing narratives is difficult, although my research has shown that the parallels and alliances between disabled and sexual stories have a long history [11]. However, what has happened to a large degree is that the stories have not had a wide public hearing. This is required to move the stories into public consciousness. According to Plummer, stories tend to evolve along five key points:

1. Stories are imagined and visualized; there is empathy for the personal stories;
2. Stories start to be told; they are announced and shared;
3. The individuals become storytellers; and identities are created;
4. These identities lead to the creation of communities and social worlds;
5. A culture of public problems is created as stories move into the public consciousness (Adapted from [8] p. 126).

For disabled or autistic LGBT+ people, the final move has not taken place. My research has shown that whilst Points 1–4 have been established, they are not complete. Point 3 suggests that storytellers are created; however, disabled or autistic LGBT+ people are not allowed to become storytellers because there is no one listening, as the storytellers are not valued. The stories being shared are dismissed because of doubts surrounding the validity of stories because of preconceptions about the populations ability to tell such stories. No one is prepared to listen, despite the consistent call for empowerment through listening to and valuing lived experience [7]. The final move has proven difficult because disabled or autistic people are not seen as experts in their own lives [13]. Point 4 has also met
strong resistance. Communities are often hidden and private due to misunderstanding and fears surrounding personal safety. Plummer’s response to this would be that communities offer a unified voice and make such stories difficult to ignore [8]. However, communities themselves are rarely truly representative and often exclusory towards those who do not fit an established preconception of what a member of such a community should look like [101].

6.4. Creating New Stories

The previous section clearly highlighted the problems in creating stories, Plummer suggests these can be somewhat tempered by the creation of stories that are convincing and timely. As Plummer notes, telling the wrong story at the wrong time can lead to setbacks and violent resistance from others (Plummer gives the example of gay bashing) [8]. Indeed, in my own research, stories of physical and verbal abuse were commonplace [14].

The stories of disabled or autistic LGBT+ people need to align with established narratives whilst being structured positively; and this is beginning to take shape. The positive stories of neurodiversity studies, disability studies (e.g., Crip Theory) and progress in LGBT+ equality offer fields to tap into. They also offer intersectional stories in the form of autsexual/autigender [44–46] and neuroqueer [47] narratives. For any of these stories to become part of public consciousness, Plummer states that there are three things that must occur:

1. There needs to be a significant number of people wanting to claim the new story and accept it in their own lives;
2. The stories need to be told openly and visibly so that others can find the stories and identify with them;
3. They have to attract the support of others who give their story credibility. Such allies do not claim the story as their own but work to empower others. (Adapted from [8], p. 129)

In order to enact these, there needs to be a sense of overall empowerment. Plummer is rather cautious in his conclusion that stories that are not ready to be accepted should remain silent. However, for disabled LGBT+ persons in this scenario that is not an option. Remaining silent perpetuates exclusion, misunderstanding, ableism and has serious implications for mental health. As a result, we need to speed up acceptance of these stories and speed up the three aspects outlined above. This could be achieved by focussing upon: giving voice, communities and visibility, and role models and allies. These practical solutions could help to move the stories into public consciousness [8].

This results in the revision of stories to more accurately reflect lived experiences. Research shows how sexuality stories for disabled or autistic people need to be adjusted in terms of understandings of capacity and the relationship between sexuality and disability or autism (e.g., sexuality is not a symptom). As experts in their own lives, these stories need to be told by the communities/activists. However, as Plummer notes, others can assist this by giving these marginalised voices platforms and working as allies when needed [8].

6.5. Implications

This analysis has suggested that to reduce barriers faced by disabled or autistic LGBT+ persons in everyday life, the sexual stories told need to be revised and re-accepted into the public consciousness. These stories need to reflect lived experiences and be positively framed, moving away from medicalisation and towards valuing the expertise of disabled and autistic LGBT+ people. At present, there are challenges due to resistance towards allowing disabled or autistic LGBT+ to become storytellers, as their expertise is often dismissed. Additionally, communities are often exclusory or not publicly visible (although often for good reason).

New frameworks for creating convincing stories are emerging, and these can align themselves with powerful and accepted templates and social spheres. Although it would appear that such stories are not ready to be heard, this needs to be addressed. Through empowerment, these stories need to be fast-tracked by ensuring that they are given voice, visibility and support.
Plummer’s suggestions are an important starting point, and sexual stories could act as foundations to build future progress. However, there are things that have happened since 1995 that Plummer could not have imagined. How, for example, are coherent stories possible with the proliferation of conflicting narratives combined with the torrent of hate-speech that is openly available to view on social media platforms, with limited moderation?

What is clear, however, is that stories need to be led by those whose lives are being explored. The history of autism research, for example, shows that allowing researchers to create theories and frameworks to organize and control lives on their terms has led to lasting damage. The stories that have become accepted are not reflective of real lives and are built upon ideas that have been disproven (the double empathy problem is a good example of a disproven idea that continues to be accepted today [102]). There needs to be a radical shift in the nature of LGBT+ research into disabled or autistic lives where researchers move to facilitators rather than experts. It is clear that such an approach would be unattractive to modern universities because such research would take time and would not fit with how funding grants are structured [9]. However, research is too often reactionary and does little to serve the communities being investigated. It is important to note that most of the important progress that research highlights is taken from activists. Autigender, for example, has been discussed online since at least 2014 and yet is only now making traction in research. This delay highlights how those who make the stories (e.g., researchers/scientists) are working with outdated modes of thinking which can only serve to benefit themselves, rather than working to improve people’s lives.

7. Conclusions

Progress in disability studies and more recently autism studies has been beneficial in framing both positively whilst also challenging long-standing misconceptions. However, when sexuality is thrown into this mix, the progress appears to be less robust and not resilient to challenge. Talking about intimacy and sexuality automatically reverts the discussion back to questioning capacity and battles which were thought to be won. Adding LGBT+ identities into this serves to accentuate this further. However, the combination of activism and emerging work in relation to neurodiversity studies (including the development of autigender/autisexual and neuroqueer) alongside critical disability studies, presents an opportunity to highlight positive disabled and autistic LGBT+ stories. It is clear that such stories have not yet been accepted and that the experts (disabled or autistic people) have not been accepted as storytellers. However, the approach I have outlined needs adaptation for contemporary life where the emphasis is placed upon valuing the voices of the experts (e.g., disabled or autistic LGBT+ persons). There needs to be a clear shift where researchers become the reflectors of the people whose lives they are analysing, rather than attempting to control them. Through empowerment, community work and heightened visibility alongside allyship, there is an opportunity to revise the stories of oppression and work towards addressing the damage that has been done.

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