Literature Review:

Care Staff Discourse of Day-to-Day Support for People with Learning Disabilities

Empirical Paper:

Care Staff Constructing the Sexuality of People with Learning Disabilities

Submitted by Victoria Booth, to the University of Exeter
as a thesis for the degree of Doctor of Clinical Psychology, April 2022

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature:

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SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

LITERATURE REVIEW

Care Staff Discourse: Day-to-Day Support for People with Learning Disabilities

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Accessible Summary

- This paper is about care staff who help people with learning disabilities in their daily lives. I looked at how care staff talk about supporting people with daily living in research that has already been completed.
- I found that care staff spoke about choice, care and compassion, and professional accountability. It seemed difficult for care staff to talk about supporting choice without rules and risk getting in the way.
- It may be helpful for care staff to know how difficult it is to talk about choice. This might help care staff support people in the best way.

Keywords: learning disabilities, daily living, care staff, discourses

Abstract

Background

Personalisation and empowerment are at the centre of providing effective care and support for people with learning disabilities. Care staff have a critical role in facilitating choice and empowerment through day-to-day support. The way people talk can influence how people are supported, therefore understanding care staff discourse is important for people with learning disabilities' daily lives.

Method

The literature of five major databases were systematically reviewed and identified 10 papers where care staff spoke about day-to-day support of people with a learning disability. These papers were summarised and critically evaluated. The data was synthesised using discourse analysis to reveal the discursive strategies used by care staff to talk about supporting people in their daily lives.

Findings

Overall, the quality of the reviewed studies was good. The design, methodology and rigor of data analysis was adequately addressed within most studies. However, good transparency was lacking with many studies inadequately reporting recruitment strategy, researcher relationship and ethical considerations.

The synthesis revealed that care staff spoke about choice, care and compassion, and professional accountability when discussing daily support. Discursive devices included the repertoire ‘not just a job’, comparative strategies, and positioning staff as teachers and people with learning disabilities as learners. These created a complex position for staff and led to a dilemma where choice was sometimes spoken about in opposition to professional accountability.

Conclusions

The identified discourses extend the original qualitative findings of the reviewed literature and are considered in reference to the crucial role that care staff play in the lives of people with learning disabilities. The discursive synthesis enabled the sparse discursive literature base to be extended, however was limited by the broad demographics of the reviewed studied. Further research and implications for clinical psychologists providing reflective spaces to raise awareness of difficult discourses are discussed.

Introduction

People with learning disabilities often face social inequalities (Public Health England [PHE], 2015) and many live in residential homes with support (Department of Health [DoH], 2009). The way we talk about people can perpetuate social inequalities and affect how people experience the world. How care staff, who are integral to daily support, describe supporting people with learning disabilities somewhat constructs the lives of those they support, which is important to explore. The historical context of care settings and current role of care staff is outlined below, followed by summarising the importance of care staff discourse.

Care Settings for People with Learning Disabilities

People with learning disabilities have historically been marginalized and some were segregated within long-stay hospitals (Jingree, 2017). After moving from institutional to community care, aspects of day-to-day living still needed improving (Forrester-Jones et al., 2002). In 2011, the Winterbourne View Panorama documentary showed distressing abuse of people who continued to live in outdated institutions (Hill, 2012). The national agenda is focused on improving community-based support (DoH, 2012) and clinical psychologists are suggested to have a key role in implementing change (Kapur, 2014).

PHE estimated that 30% of the adults with learning disabilities in England lived in residential homes in 2015 (DoH, 2009). Residential homes adopted more individualised approaches to care such as person-centred planning (Dowling et al., 2007), in line with ‘Valuing People Now’ which prioritised personalisation for improving service provision (DoH, 2009). Empowering people is at the centre of transforming care (Association of Directors of Adult Social Services et al., 2015). Individualised, community-based care is significant progress over institutions, but places care staff in roles with considerable power and responsibility over the lives of those they support.

The Role of Care Staff

Getting the right care and support is important to people with learning disabilities (Mencap, 2016b), alongside choice and independence, good relationships, activities and valuable social roles (Haigh et al., 2013). Staff are critical in enabling or disenabling fulfilling lives for people, through facilitating access to the world and providing care and support (Haigh et al., 2013). Service users value the interpersonal attributes of care staff alongside their practical skills and knowledge (Dodevska & Vassos, 2013). The social networks of people with learning disabilities are often characterised by their relationships with support staff and those they live with (Mencap, 2016a). Care staff constitute a large part of people's social world due to the reliance on their support and lack of social opportunities. This demonstrates the multitude of personal attributes, practical skills and knowledge needed to provide good care, and the important role of care staff in people's daily lives.

Care staff must also work within relevant legislation and frameworks, including the Care Act (2014) which states that people require support which makes their lives better whilst safeguarding from potential harm. The Mental Capacity Act (DoH, 2005) outlines the process if someone is suspected to lack capacity, and best interest decisions. Deprivation of liberty safeguards apply to those living in residential homes which state that no one should be deprived their liberty unless through a process prescribed by law. Care providers must also abide by Care Quality Commission (2021) guidelines to uphold good standards of care. Working within these frameworks, care staff must both protect people with learning disabilities whilst supporting and empowering their rights.

It can be difficult for care staff to balance protective responsibility with service user rights (Robertson & Collinson, 2011). Support workers have described a tension between duty of care and promoting independence, which is sometimes managed by staff deviating from standardised procedures to allow independence (Hawkins et al., 2011). People with learning disabilities are suggested to continue to have limited control over their lives, partly due to service rigidity and policies that conflict with their choices (Jingree & Finlay, 2013). Perhaps processes intended to uphold people with learning disabilities' rights somewhat hinder staffs' ability to promote choice and independence.

Jingree (2009) argued that care staff face a dilemma between enabling choice and person-centredness, whilst following principles of normalisation and promoting socially acceptable choices. Antaki et al. (2007) also suggested that the social processes and institutions designed to support people can further disable them. When staff were attempting to elicit service user views this interaction constructed the identity of the residents as incompetent and dependent, and the identity of staff as knowledgeable and in charge (Antaki et al., 2007). This process of encouraging people to voice their views instead disempowered them by treating them as needing coaching, reinforcing an impairment identity for people with learning disabilities. Another study found care staff faced a conflict between promoting decision making and duty of care (Jingree et al., 2006). This demonstrates the power and responsibility inherent within the role and daily difficulties care staff face supporting people with learning disabilities.

Care Staff Discourse

Discourse is the language and talk people use, which is socially constructed and able to create and perpetuate social inequalities, and particularly relevant when studying people embedded in institutional settings (Potter, 2005). Discourse analysis views talk as social interaction and explores the strategies that people use to enable those interactions (Potter, 1996). Discursive approaches are underpinned by social constructionism which suggests that language is central in constructing the ideas and social processes that create our social world (Potter, 2003). The language used to describe people can also influence expectations and interactions (Haegele & Hodge, 2016). The discursive context constructed by care staff is likely significant in how people with learning disabilities experience their daily lives within residential settings.

Discourse can impact how people experience the world; dominant discourses impact societal assumptions and expectations, and ultimately how people interact with those with a learning disability. Societal discourses therefore have the power to affect the people it categorises. For example, one study found that women with learning disabilities drew on negative constructions of people with learning disabilities during their own discourse (Scior, 2003). Dominant discourses within society can negatively impact how people talk about and construct themselves.

The effect of damaging social discourses was raised by people with learning disabilities who argued that narratives which positioned them as a burden negated their humanity and worth as valued individuals (Brown et al., 2021). Given how significant care staff are in supporting people with learning disabilities it is important to know if these social discourses are perpetuated by staff. People with learning disabilities have spoken about the powerful position staff hold due to their reliance on them, and how frustrating it is when they are let down or treated unfairly (Hoole & Morgan, 2011). Given the power imbalances inherent in the relationship, understanding care staff discourse is particularly significant.

Literature exploring challenging behaviour (CB) for people with learning disabilities demonstrates the relevance of care staff discourse. NICE (2015) guidelines describe CB as behaviour that is a challenge to services and carers, and results from the interaction between personal and environmental factors including aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. Yet the term CB is a social construction; an umbrella term used to describe a variety of unwanted behaviours when displayed by a person with a learning disability.

Considering this, research has explored care staff discourse on CB. Interviews revealed dominant individual pathology discourse which constructed the behaviour as inherent to the individual's pathology, or context discourse which constructed the behaviour as an understandable reaction to their situation (Wilcox et al., 2006). A recent study found that CB discourse continued to reflect the medical model of disability (Nunkoosing & Haydon-Laurelut, 2011). Addressing CB discourse has not been directly researched, however, one study used video interactive guidance for staff working with children with learning disabilities displaying CB (James et al., 2021). Highlighting staff interactions changed the narratives and perspectives to be more relational, and impacted the support offered (James et al., 2021).

Whilst CB discourse has been somewhat explored in the literature, there is limited research on staff discourse about daily living, choice and empowerment for people with learning disabilities. Discourse has the power to perpetuate or challenge social constructions and inequalities, and impact support. Given the significant role of care staff supporting people with learning disabilities in daily living, it is important to understand day-to-day support discourse, as this could impact people's experience of their daily lives.

Research Question

This review aimed to identify and critically appraise the literature pertaining to the following research question:

What discourses do care staff use in the existing literature to talk about supporting individuals with a learning disability in their day-to-day living?

Method

A meta-synthesis of the literature was conducted using a systematic search strategy, synthesised by abstracting discourses used by care staff discussing supporting people with learning disabilities. This review follows the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses (PRISMA, 2020) guidelines to ensure all recommended information is reported (Page et al., 2021). The inclusion/exclusion criteria were based on the SPIDER framework in Table 1 (Cooke et al., 2012) to examine qualitative studies where care staff spoke about supporting individuals with a learning disability.

Table 1

SPIDER Framework for the Inclusion and Exclusion Criteria

	Inclusion	Exclusion
Sample	Residential/supported living care/support workers working with adults with a learning disability	Non-care staff e.g., parents, healthcare workers, social workers, teachers, people with learning disabilities Staff working with children/adults without a learning disability Staff only working with children with a learning disability Forensic/inpatient settings
Phenomenon of Interest	Care staff talking about day-to-day support of adults with a learning disability	Specific support with life events/situations not day to day living e.g., dementia, bereavement Focus only on challenging behaviour Training programmes or interventions Unrelated topic to supporting adults with learning disabilities
Design	Interview Focus Groups	Observations Case studies Questionnaires or surveys Written text Meeting notes
Evaluation	Discussion or talk Analysis (thematic, discourse, narrative, interpretative phenomenological analysis, grounded theory)	-
Research Type	Qualitative methodologies Mixed methods if qualitative data is reported separately Peer-reviewed journal articles Studies published in English	Quantitative methodologies Book chapters, editorials, opinions or discussion, literature reviews, meta-analyses, grey literature Studies not published in English

Papers exploring support related to specific life events or situations were excluded (e.g., dementia, bereavement) as these are likely too specific and not reflective of typical daily living. Articles focused on CB were also excluded as this is another specific area of support where discourses may represent distressing interactions or conflict rather than everyday language and has been examined elsewhere.

Search Strategy

Five key electronic databases (Web of Science, PsycArticles, PsycInfo, PubMed Central and Medline) were searched in November 2021. Search terms are shown in Table 2 and were developed through scoping reviews. Grey literature was not included due to time limitations. The included publications' reference lists were hand searched for relevant articles not identified by the initial search, which were title and abstract screened, in line with NICE guidelines (2012).

Table 2

Search Strategy Terms

Concept	Search Field	Search Terms
Learning Disability	Title	Learning disabilit* OR Intellectual disabilit* OR Developmental disabilit* OR Intellectual impairment OR Mental impairment OR Mental* disability* OR mental* handicap OR mental* retard*
Support staff	Title	Support workers OR Carer* OR Staff OR Support staff OR Care staff OR Institution* staff OR Residential
Discourse	Title or Abstract	Discourse analysis OR Discursive OR Talk OR Argument OR Rhetorical OR Interview OR Focus group OR Qualitative OR Repertoire OR Discuss* OR View*
Support	Title or Abstract	Support OR Role OR Job OR Facilitate* OR Help OR Decision OR Care

Screening

The search identified 844 articles, 683 after the removal of duplicates. The screening process is shown in Figure 1 and included title and abstract screening based on the SPIDER inclusion/exclusion criteria, before assessing eligibility from full text review. A second independent rater reviewed 6 full text articles using SPIDER to assess eligibility for inclusion. Inter-rater agreement was 100% indicating good reliability of study selection.

Figure 1

PRISMA Flow-Chart

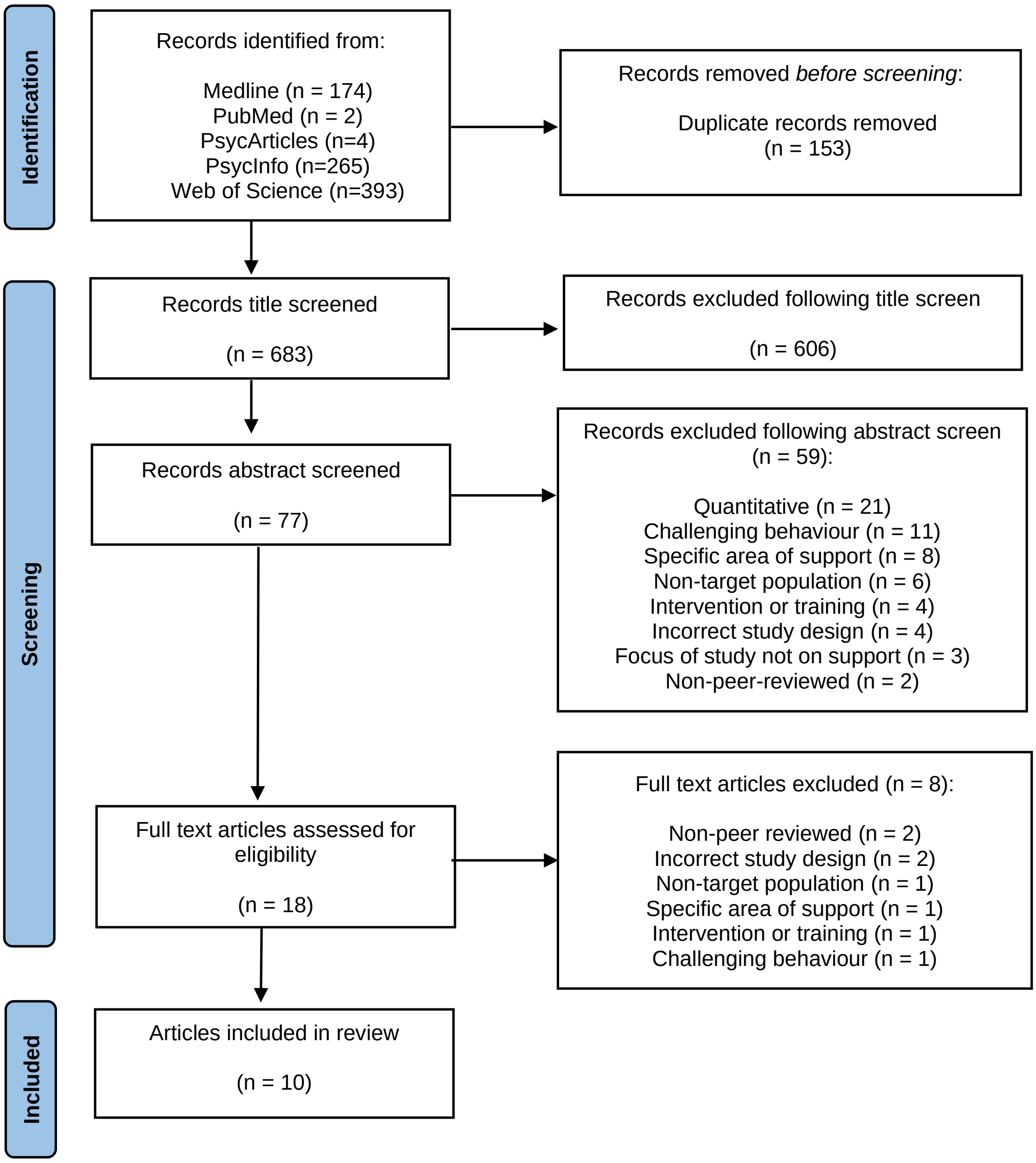


Table 3

Reviewed Study Characteristics

Reference	CASP Score	Aim	Design and Analysis	Data	Risk of Bias/Limitations	Findings and Clinical Relevance
#1 Dunn, M. C., Clare, I. C., & Holland, A. J. (2010). Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellect Disability Research, 54*(2), 144-160.	21	To explore how the introduction of statutory legal regulation under the MCA interfaces with the practical and ethical dynamics of care and support of people with learning disabilities living in residential care homes.	Qualitative design with a constructivist grounded theory approach.	Semi-structured interviews with 21 support workers and observations of everyday care practices from three residential homes.	The study was based on three residential care homes, so is limited in generalisability. The findings explore participant perceptions and may not reflect actual practice. The individual interviews did not allow for exploration of the dynamics between staff when discussing decision-making.	Support workers described aiming to make substitute decisions which helped residents 'live a life like ours' and gave a moral account of using their own day-to-day life experiences to improve the day-to-day experience of residents. Support workers also described seeking to support residents to live their lives in ways the support workers judged to be meaningful.
#2 Hermsen, M. A., Embregts, P. J., Hendriks, A. H., & Frielink, N. (2014). The human degree of care. Professional loving care for people with a mild intellectual	16	To identify care staff motivation for working as a care professional, the conditions for providing professional loving care, the effects of	Qualitative design with grounded theory approach to code data.	Semi-structured interviews with 28 care staff working at five care organisations for people with learning	The study is based on five care organisations in one geographical location, so is limited in generalisability.	Care staff described building a trusting relationship with people with learning disabilities and recognising they are at the base of professional loving care. Care staff perceived the precedence given to smooth running of organisations over direct contact with people to

disability: an explorative study. *Journal of Intellectual Disability Research*, *58*(3), 221-232.		commercialisation of care and what is needed to rearrange and adjust care in the future.		disabilities in the Southeast of the Netherlands.		be a threat to quality of care. It is suggested that the gap between visions of care and experience of good care needs to be bridged by care organisations.
#3 Hutchison, A., & Kroese, B. S. (2016). Making sense of varying standards of care: the experiences of staff working in residential care environments for adults with learning disabilities. *British Journal of Learning Disabilities*, *44*(3), 182-193.	24	To examine front-line staff experiences of working in residential care for people with learning disabilities; specifically how experienced care staff perceive and make sense of their role in relation to current and past practice.	Qualitative design using interpretive phenomenological analysis.	Semi-structured interviews with six front-line care workers who had each worked for over five years in more than one residential care setting.	The researcher reflects on their own experiences which could bias analysis and interpretations, and strategies used to minimise undue bias.	The main themes were; the degree of positive relationship reciprocity care staff has with colleagues, service users and managers, their role being consistent or congruent with their underlying values and intrinsic motivation for their work, and their experiences of environmental and organisational constraints. These have implications for how services could improve care practices.
#4 Jingree, T. (2015). Duty of care, safety, normalisation and the Mental Capacity Act: a discourse analysis of staff arguments about facilitating choices for people with learning disabilities in UK services. *Journal of Community & Applied Social Psychology*, *25*(2), 138-152.	20	How support workers argue about empowering service users with learning disabilities and manage dilemmas of facilitating independence, choice and control against institutional agendas.	Qualitative design using critical discursive psychology to analyse.	Semi-structured interviews with 15 support workers at a service providing residential and day support for people with learning disabilities.	The researcher does not detail reflexivity or state their position to the topic, which has the potential to influence discourse analysis.	Staff utilised repertoires about ‘duty of care’ and produced staff positions of granting and withholding choice and being responsible. Some staff justified positioning service users as lacking capacity and invoked repertoires about ‘safety’ and ‘normalisation’ with implications for facilitating choices. Alerting staff to these discourses may resolve practical dilemmas and help empower people with learning disabilities.

#5 Jingree, T., & Finlay, W. (2008). 'You can't do it... it's theory rather than practice': staff use of the practice/principle rhetorical device in talk on empowering people with learning disabilities. *Discourse & Society, 19*(6), 705-726.	20	How care staff talk about choices and control in the context of other institutional policies and practices, and how these tensions were organised in participant talk in managing ideological dilemmas.	Qualitative design using discourse analysis.	Semi-structured interviews with 15 professional caregivers of people with learning disabilities.	The researcher does not detail reflexivity or state their position to the topic, which has the potential to influence discourse analysis.	Dominant discursive themes used by care staff were increasing autonomy which centred on discourses about freedom of choice and individual action, and practicalities talk which justified why choices and control could not be increased for some residents. Revealing oppressive discourses may offer the potential for social change through adopting alternative discourses.
#6 Petner-Arrey, J., & Copeland, S. R. (2015). ‘You have to care.’ perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities, 43*(1), 38-48.	21	Aimed to explore how people with learning disabilities and support workers perceive the role of the support worker in assisting with autonomy? What are the experiences of support workers and people with learning disabilities in regard to the autonomy of people with learning disabilities and what factors promote or inhibit autonomy in support settings?	Qualitative design using thematic analysis.	Semi-structured interviews with 10 adults with learning disabilities who had received care and were able to communicate in an understandable manner, and 10 support workers who currently or recently worked with people with learning disabilities in a residential setting.	A small sample size was used, and demographic information not collected, so it is difficult to ascertain if results are representative of all support relationships. The study also explored perceptions not direct observations so may not be consistent with actual practices.	Support workers and people with learning disabilities faced challenges that restricted the promotion of autonomy, and to effectively promote autonomy support workers had to care about their work with individuals with learning disabilities. The findings are discussed in light of implications for how policies on health and safety are developed and communicated, the limitations of and need for flexibility in current system structures, recruitment and rota procedures, and training programmes.

#7 Quilliam, C., Bigby, C., & Douglas, J. (2018). Being a valuable contributor on the frontline: The self-perception of staff in group homes for people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 395-404.	22	To explore the self-perception of frontline staff about their role in group homes for people with learning disabilities, using the broad question; How do staff perceive their work?	Qualitative design using a constructivist grounded theory methodology.	Semi-structured interviews with 14 staff working in group homes in Victoria, Australia. Two group interviews with group home residents and observations of everyday service events.	These findings are particular to the homes that participated in one geographical location. It is also difficult to gain rich data with people who could be considered oppressed because they are usually more vulnerable in the research process.	Staff considered themselves valuable contributors to group home service, yet also felt powerless in their role. These paradoxical experiences meant frontline staff were proud of their work but also stressed and exhausted. These findings inform understanding of frontline staff experiences and have implications for improving quality of service provision.
#8 Salmon, R., Holmes, N., & Dodd, K. (2014). Reflections on change: Supporting people with learning disabilities in residential services. *British Journal of Learning Disabilities, 42*(2), 141-152.	20	To explore the reflections of staff about rule-bound care practices and their experience of changes in these. What factors supported the change to, and continued adoption of, person-centred care.	Qualitative design using interpretative phenomenological analysis.	Semi-structured interviews with seven staff at two residential homes for people with learning disabilities.	The strengths and limitations of this paper are not commented upon; therefore it is difficult to assess the risk of bias.	Staff spoke about their first experiences of caring for people in large institutions, the ‘old ways’ of working, contrasted the positives and negatives of these in supporting people with learning disabilities, and the changes they had experienced in practice. The experiences of staff have implications for training, supervision and reflective spaces to support staff working in these contexts.
#9 Sandjojo, J., Gebhardt, W. A., Zedlitz, A. M., Hoekman, J., den Haan, J. A., & Evers, A. W.	20	To explore what people with learning disabilities and those who support them think of	Qualitative design using a general inductive approach to analyse the data.	Focus groups were held with seven people with learning disabilities, 13	The sample was small and only included participants from one care	It was found that all people with learning disabilities need at least some support but would like to become more independent. Barriers are experienced when staff

(2019). Promoting independence of people with intellectual disabilities: A focus group study perspectives from people with intellectual disabilities, legal representatives, and support staff. *Journal of Policy and Practice in Intellectual Disabilities, 16*(1), 37-52.		‘independence’ and to gain insight into which barriers they experienced when wanting to promote independence. To examine what participants thought could be advantageous and disadvantageous outcomes of people with learning disabilities having greater independence.		legal representatives and 17 support staff of people with learning disabilities from a care organisation for people with learning disabilities in the Netherlands.	organisation, and participants with mild to borderline learning disabilities not moderate to severe.	try to promote independence: time limitations, not knowing how to promote independence, fearing things might go wrong. Both staff and family members tend to take tasks away from people with learning disabilities, limiting opportunities for them to learn new things. To promote independence, more support time is needed, and clear individualised stepwise approaches, with adequate communication.
#10 Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities, 38*(4), 310-318.	23	To explore how Community Learning Disability Teams can provide support and training to support workers for adults with learning disabilities, by understanding how support workers perceive their role, training and support needs.	Qualitative design using a phenomenological approach.	Focus groups and semi-structured interviews with eight support workers working with people with learning disabilities.	The researcher was an employee within the service and had a duty of care both to the research participants and people they support, and communicated this which could have influenced the openness of the participants.	Maximising quality of life was a primary aim for staff who identified with a facilitative and care provider role. The vulnerability of those they support was a concern for staff. There was an emphasis on trial-and-error learning for support workers, which has implications for skill development, management and supervision. Effective working was another key theme, with poor communication and assertiveness skills preventing good joint working.

Quality Appraisal

The CASP Qualitative Studies Checklist (2018) was used to assess the quality of the identified articles based on eight criteria. The scoring system suggested by Duggleby et al. (2010) and since replicated (e.g. Loughlin et al., 2020; Rushbrooke et al., 2014) was used where each criteria scored 1-3 dependent on being fully addressed, partially addressed, or barely addressed. Table 3 includes the CASP ratings for each study with a maximum score of 24. Studies were not excluded based on their CASP score. A second-rater reviewed the quality of 3 studies to test agreement between raters (Cohen, 1960). These were weighted to account for the extent of difference (Cohen, 1968) and inter-rater agreement was good (*Kappa* = 0.68). Differences were discussed and final ratings agreed upon.

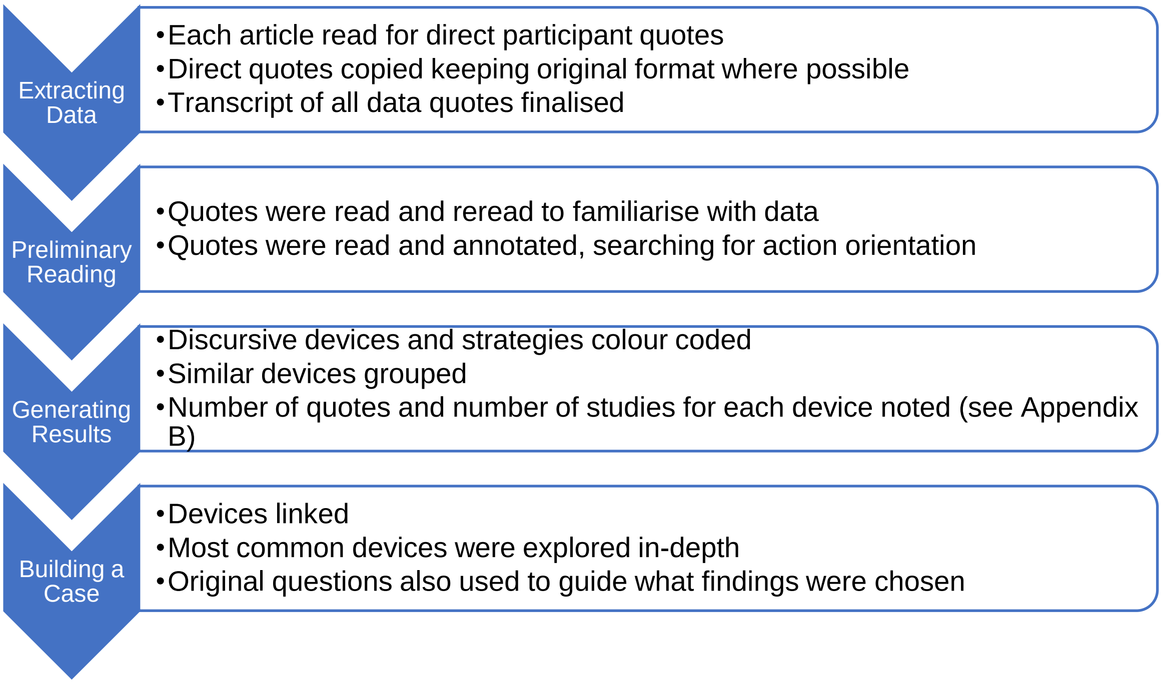
Method of Data Synthesis and Credibility

Care staff quotes were extracted, not the researcher’s interpretation or analysis of data. The extracted quotes were organised by paper and given line numbers as not all provided this information. Extracts are coded in this review by paper number, page number, line number (#X, Y, Z). Data quotes started and ended on lines as presented originally.

Discourse analysis was conducted following guidelines by Goodman (2017) to analyse these quotes and included preliminary reading of the text, identifying discursive devices and strategies, and building a case to support findings. Discursive devices included subject positions (the ways that people are located through talk), repertoires (repeated way of talking about something which categorises it in a way that is culturally understandable), and ideological dilemmas (opposing ways of understanding the same concept) (Wiggins & Potter, 2017). To demonstrate trustworthiness and transparency (Greckhamer & Cilesiz, 2014) the systematic data analysis process is outline (Figure 2). An example of the data annotations and colour coding is shown in Appendix A, and the list of identified devices and frequencies is shown in Appendix B.

Figure 2

Data Analysis Process



Extracting Data

- Each article read for direct participant quotes
- Direct quotes copied keeping original format where possible
- Transcript of all data quotes finalised

Preliminary Reading

- Quotes were read and reread to familiarise with data
- Quotes were read and annotated, searching for action orientation

Generating Results

- Discursive devices and strategies colour coded
- Similar devices grouped
- Number of quotes and number of studies for each device noted (see Appendix B)

Building a Case

- Devices linked
- Most common devices were explored in-depth
- Original questions also used to guide what findings were chosen

Findings

The study characteristics, findings and quality appraisal of the 10 included papers are summarised in Table 3. All studies included direct quotes from staff who supported people with learning disabilities in residential settings, with 197 quotes extracted for analysis. Each quote cannot be directly linked to the participant; therefore, this analysis may not fully represent the 140 participants. The overall demographic information of staff participants, care setting and recruitment methods are reported in Table 4.

The study characteristics and participant demographic information are similar for papers #3 and #4, which suggest these used the same data set. The studies reported different quotes, and do not confirm they are from the same data set, so have been included separately.

Study Methodology

The papers utilised various qualitative methodologies; phenomenological (*n*=*3*), grounded theory (*n*=*3*), discursive (*n*=2), general inductive (*n*=*1*) and thematic (*n*=*1*). Most used semi-structured interviews (*n=8*), focus groups (#9) or a combination of both (#10). Three studies also included people with learning disabilities (#6, #7, #9), and one included legal representatives (#9), all reported separately to staff quotes. Two studies observed staff and service users in day-to-day support (#1, #7).

Most studies asked general questions about experiences working in residential care supporting people with learning disabilities (#3, #4, #5, 6, #7, #8, #10). Most also asked about specific aspects of support; decision making (#6, #8), choice and control (#4, #5), independence and empowerment (#1, #9) and rules and routines (#8). One study explored the commercialisation of care (#2) and one focused on changes in care practices over time (#3). The broad questions and methodologies somewhat limit the current paper's analysis as the original research designs did not intend to answer the current research question.

Study Participants

The sample size of care staff participants ranged from 7 to 28 (*M =14.1*) and totalled 140. Eight studies reported participant sex; there were more women than men. Only four reported participant ethnicities, three included all white British staff and one reported staff were ethnically and racially diverse. The ages and length of work experience of participants within the sample were broad (see Table 4). Most studies were conducted in the UK (*n = 6*), in addition to two studies from the Netherlands, one from the USA and one from Australia (Figure 3).

Four studies sampled staff working within one trust or organisation (#4, #5, #9, #10), and six included staff working across residential homes or care organisations (#1, #2, #3, #6, #7, #8). Seven studies reported their recruitment methods and most used convenience sampling by contacting care organisations (#1, #6, #7, #8, #9). One used purposive sampling through forum adverts (#3) and one was conducted internally by the service (#10).

Table 4

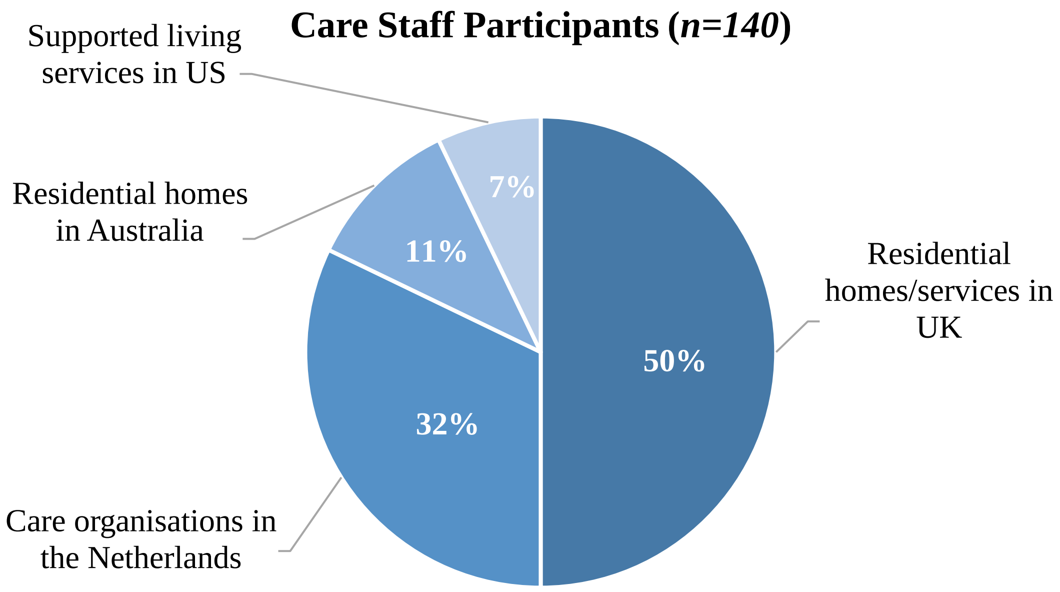
Demographic Information of Studies

Paper	Participants	Sex	Age range (years)	Ethnicity	Length of Care Experience	Time in Current Service	Care Setting	Recruitment Strategy
#1	19 support workers	-	-	-	2 months to 27 years	2 months to 22 years	Three residential homes in the UK, two large houses with self-contained flats, one small four-bedded bungalow	Homes were identified and care managers contacted for expressions of interest
#2	28 care staff	18 females 10 males	20 to <50	-	>5 years to <30 years	-	5 care organisations for people with learning disabilities in the Southeast of the Netherlands	-
#3	6 front-line care workers	4 females 2 males	28 to 52	-	5 years to 24 years	-	Participants had worked in small (three bed) multiple occupancy homes and large-scale (>30 bed) residential facilities in the UK	Purposive sampling through adverts on forums, then snowball or referral sampling
#4	10 staff members 5 managers	12 females 3 males	22 to 59	All white British	-	4 months to 19 years	A UK trust providing residential and day support for people with learning disabilities and epilepsy	-

#5	15 support workers	12 females 3 males	22 to 59	All white British	-	4 months to 19 years	A UK trust providing residential and day support for people with learning disabilities and epilepsy	-
#6	10 supported living support workers	7 females 3 males		Ethnically and racially diverse	1 to 20 years	-	Provided support to people with learning disabilities in urban and rural areas in the south-western United States	Local support services contacted for interest
#7	2 supervisors 13 support workers	-	-	-	-	-	One rural and two metropolitan homes for adults with learning disabilities in Australia	Convenience sampling by speaking to care managers to determine interest
#8	7 staff members	5 females 2 males	46 to 53	-	24 to 28 years	2 ½ years to 6 years	Two UK residential homes on the grounds of an old long-stay hospital. Each home had 8-9 adults with learning disabilities living there	Staff were encouraged to participate via information sheets given at staff meetings
#9	17 staff members	12 females 5 males	24 to 53	-	5 to 33 years	-	A care organisation in the Netherlands for adults with learning disabilities	Recruited through a care organisation
#10	8 support workers	5 females 3 males	26-35 to 55-65	All white British	-	<1 year to >10 years	A joint health and social care service in a large British city for adults with learning disabilities	The researcher and participants all employed by the service

Figure 3

Demographics of Care Staff Participants



Study Quality

The quality of reviewed literature was generally good, with all studies addressing the rigor of data analysis and value of the research. Nine studies addressed appropriateness of the research design, one partially addressed this (#2). Four studies did not detail the recruitment strategy (#4, #5, #8, #10), affecting transparency. The relationship between researcher and participants was not considered in most studies (#1, #2, #4, #5, #6, #7, #8, #9), limiting understanding of potential effects on data analysis. Ethical considerations were only fully addressed in six studies (#3, #6, #7, #8, #9, #10).

Synthesis of Extracted Data

The extracted quotes were analysed to reveal discourses care staff used to talk about supporting people with a learning disability in their day-to-day living. Findings revealed that choice, care and compassion, and professional accountability were navigated through talk. Staff used discursive strategies which accounted for the type of support they described providing. These persuaded the listener that the support was justified, but the need to account for support suggests this may not always be accepted.

‘Not just a job’

Within the data the idea that supporting people is *‘not just a job’* was repeated, which perhaps positioned staff as caring and compassionate. Working with people with learning disabilities was described as *‘my thing, my passion’* (#2, 10), which constructed the role as being part of staff’s identity. The person-centred nature of the role was directly stated and alluded to, *‘these are people’* (#6, 19), which positioned staff as caring and compassionate. This was used alongside talk of boundaries, *‘you are not supposed to get too close’* (#7, 21), which created a dilemma between care and compassion, and the need for boundaries, and seemed to justify the relationships described between staff and people with learning disabilities.

Table 5

‘Not just a job’ repertoire data extracts

Paper	Page	Lines	Data
#2 Hermsen et al. (2014)	1	10-12	*I still think it is great to work with them [people with IDs]. It is simply my thing, my passion. How you see people, how you interact with them, I think that everything revolves around that and especially in care.*
#6 Petner-Arrey and Copeland (2015)	1	18-19	*It’s not fair to come in and it just be a job and be a paycheck. These are people, they have emotional needs. They have feelings.*
#7 Quilliam et al. (2018)	1	21-22	*I just love the guys here… You are told you are not supposed to get too close to the guys [residents] but it is impossible not to… because I’ve been here for so long.*

Comparative Strategies

Extract 1: What would I do? (#1, 1, 23-31).

P2*: Well, they come home, and they know they're going to get a drink . . . then they give you a sign that they want [a biscuit], yeah fair enough because their dinner's going to be in another 2 hours... it's like me, I could eat cake all day and eat junk food, so you use your common sense, and you think, 'what would I do? What would I like?'*

MD: *And so if you decided it was right, you would give them a biscuit even if that wasn't the norm?*

P2*: Yeah, because we'd do the same wouldn't we. We shouldn't deny them things like that, you've just got to be sensible about it: 'would I do that? Is it right?*

Within the data staff used comparative strategies to account for the type of support they described providing. One strategy brought themselves into the scenario and used a comparison to their own wishes. A staff member described in Extract 1 when a person with learning disabilities asked for a biscuit before dinner they thought, *'what would I do? What would I like?'* (26) to decide how they should respond. These questions related the situation to the staff members own life to justify the support provided by asking, *'is it right?'* (31). These comparisons positioned staff as advocating for choice and supporting people in a caring and compassionate way.

Extract 2: It Happens to Everybody (#4, 3, 75 – 88).

I *Why because you might be giving them a non-alcoholic wi[ne and they think*

R *[and*

I *it's an alcoholic wine?*

R *Either that or just (–) the fact that they have to take an alternative.*

I *Erm yeah but then again you see it's a choice.*

80 ***R** Umm*
81 ***I** We offer the choice. You know erm professionally we would be (–) not very responsible if*
82 *we were if somebody were to knock back erm four glasses of wine in you know you know*
83 *and that wouldn't be good for them because of their medical condition and their epilepsy.*
84 *Erm you would obviously er just like a pub isn't it? If someone had too much to drink you*
85 *would find you know you're not gonna serve them are you?*
86 ***R** Umm*
87 ***I** So it's the same thing isn't it? (–) (Big) deal about it and just sensible with that. And that*
88 *happens on site and outside, to you and me and to everybody so.*

The other comparative strategy compared the support described to what is done to people in other situations, such as being denied alcohol in a pub (Extract 2). The moderator asked what effect giving people with learning disabilities non-alcoholic wines had on the choices they made. The staff member responded they might think it's alcoholic wine (77). The staff member stated this is *'a choice'* (79) and that if someone drank four glasses of wine with medical conditions and epilepsy it would not be responsible professionally (81-83). The comparison of being denied alcohol in a pub *'if someone had too much to drink'* (84) likened the support described to what would happen in a pub setting. The staff member concluded, *'it's the same thing isn't it?'* (87) and stated it happens to *'you and me and to everybody'* (88). The comparison to how someone would be treated in another setting (a pub) was used to make the described support seem reasonable and difficult to disagree with.

Extract 3: Normal Things (#1, 3, 102-115).

102 ***P5:** Yeah, that's something that I'm really keen on.*
103 *The great thing about living here is that*
104 *people have a good life, a good social life, they*
105 *can have fun together.*

106 ***MD:*** *And how do they have . . .*
107 ***P5:****... it's the same as us, I get them sitting*
108 *down to watch the big football matches together,*
109 *having a kick around the garden afterwards, we*
110 *often have film nights and we make a real occasion*
111 *of it. You know, popcorn, lights out, all sat*
112 *here together, it's all about them being social,*
113 *doing these things together, you know normal*
114 *things, not living like hermits, where it's all 'his*
115 *activities are different to her activities'.*

Alongside comparative strategies, the concept *'normal life'* was used (Extract 3). When asked about activities the staff member stated that *'people have a good life'* (104) and used the comparison, *'it's the same as us'* (107). The comparison to *'us'* convinces the listener that activities for people with learning disabilities are the same, building an argument that staff treat people the way they would want to be treated. Different activities were described (108-111) and it was stated these are *'normal things'* (113-114), which positioned staff as doing *'normal things'* and supporting this for people with learning disabilities.

These strategies compared the support described to how staff would want to be treated, how people might be treated in other contexts, and a normal life. These comparisons accounted for the support that was spoken about and built an argument that justified this support. Within this argument staff were positioned as supportive of choice, and working with care and compassion, but also being professionally accountable.

Teaching and Learning

Within the data staff positioned themselves as needing to teach people with learning disabilities, and people with learning disabilities were positioned as needing to be taught.

Extract 5: Teaching Things (#9, 1, 10-12).

10 *A while ago we got a question from someone who wanted to manage his own*
11 *medication … We started training and now it goes really well. So in fact, you're*
12 *always working on teaching things … and that promotes independence.*

In Extract 5, a staff member described a person asking *'to manage his own medication'* (10). The act of asking suggested staff were in charge, which positioned staff as powerful and holding authority. The staff member stated *'we started training'* (11) which constructed them as knowledgeable, and positioned staff as teachers. This positioned people with learning disabilities as needing to learn and dependent on staff. The staff member stated they are *'always working on teaching things…and that promotes independence'* (11-12), which constructed a never-ending process of reliance on staff teaching independence, creating a discourse that disempowers people with learning disabilities.

Extract 6: Start Learning (#5, 2, 47-58).

47 ***D*** *I think it's theory (word) again the idea is great because it's*
48 *giving them the ability and the (where of all) to choose. But to*
49 *be fair it depends on their level of disability because some of*
50 *our clients couldn't. So what happens then to the money, who*
51 *chooses? You know I think that choices, these choices would*
52 *need to be made for them. I think they they need to start*
53 *learning numeracy sessions, because some of them could just*
54 *go out and blow it on fags, to be perfectly, to BE HONEST!*
55 *There are smokers here there are you know erm and they*
56 *would see it as heyyyyy! I'm not saying they would*
57 *do all that to all their money but if they had more money they would*
58 *spend it!*

Within this teaching and learning discourse people's ability was spoken about. In Extract 6 the staff member stated that giving people control over their money *'is great because it's giving them the ability'* (47) which constructed control and choice as something that is given. A disclaimer presented the idea as positive, and then rejected it *'but to be fair it depends on their level of disability'* (48), and ability was used to judge whether control and choice can be given. The staff member stated that *'they need to start learning numeracy sessions'* (52), which positioned people with learning disabilities as learners. An extreme case formulation of smoking was argued *'if they had more money they would spend it'* (57) and legitimised not giving people choice and control. Ability, risk and practicality were used to oppose giving people choice due to professional accountability.

Professional Accountability

These discursive devices created a complex positioning of staff; supportive of choice, caring and compassionate whilst having the power to give choice and needing to be professionally accountable. The repertoire *'not just a job'*, comparisons to how people are treated, and talk about teaching and learning all helped care staff navigate talking about choice, care and compassion. On the one hand this positioned staff as advocates of choice, caring and compassionate, yet also included arguments about ability, practicalities and risk. This created a dilemma where staff talked about choice as opposing professional accountability.

Extract 7: Right, Choices and Duty of Care (#4, 1, 3-10).

3 ***M*** *And that you know I think in some cases that has got to override rights and*
4 *choices. (Few lines omitted for clarity). Is you know is this very fine delign (–)*
5 *line between giving the residents rights and choices and our duty of care.*
6 ***R*** *Umm*
7 ***M*** *And you know you you are walking a a tight-rope a lot of the time.*

8 ***R*** *Umm*
9 ***M*** *We're obviously trying to give residents as much rights and choices as possible. (–)*
10 *But by the same token you do not want them taking any unacceptable risks*

Within Extract 7 the staff member positioned themselves as wanting to give choice, but used arguments about risk, practicalities and duty of care to argue against it. This dilemma was described as walking *'a tightrope'* (7) which presented this as a precarious position for staff. The staff members' use of *'obviously'* (9) persuaded the listener that giving rights and choice was clearly their position. This was followed by a disclaimer of *'unacceptable risks'* (10) which argued that this practice would be wrong, creating a complex position for staff navigating choice and risk.

Discussion

A thorough analysis of care staff quotes presented in 10 qualitative papers revealed discourses about day-to-day support for people with learning disabilities. The reviewed literature was good quality, demonstrating adequate analysis, design and rigor, although had limited transparency on researcher relationship and ethical considerations. The discursive synthesis identified the repertoire *'not just a job'*, comparative strategies which were used to account for the support described, and a teaching and learning discourse which positioned staff as needing to teach, and people with learning disabilities as needing to learn. These discursive strategies were used to negotiate an apparent conflict between choice, care and compassion and professional accountability.

Most of the reviewed papers utilised non-discursive methodologies. These original findings will be compared to the discourses identified by this current review. The original studies reported themes of care and compassion; staff saw themselves as 'more than just support workers' (Quilliam et al., 2018), were passionate about their role (Hermsen et al., 2014), and saw their role as either congruent or incongruent with who they are as a person

(Hutchison & Kroese, 2016). The current paper extends this understanding as the repertoire *‘not just a job’* was used to justify staff relationships with those they support, constructing care and compassion in conflict with professional boundaries. Interestingly, the previous studies did not identify teaching and learning themes, but this discursive synthesis revealed how talk about maximising quality of life (Windley & Chapman, 2010) and promoting independence (Petner-Arrey & Copeland, 2015; Sandjojo et al., 2019) resulted in care staff being positioned as needing to teach, and people with learning disabilities as needing to learn. There were themes of rights, choice and independence (Salmon et al., 2014; Sandjojo et al., 2019), alongside a struggle for staff between promoting autonomy and choice versus protection and risk-management (Petner-Arrey & Copeland, 2015; Windley & Chapman, 2010). The discursive lens of this review demonstrates how these two themes were negotiated within talk; either as a direct argument or indirectly positioned as conflictual.

The reviewed discursive studies are supported and the current review demonstrates how these discourses are found within other qualitative literature. Jingree and Finlay (2008) found talk about increasing autonomy, rights and choice, and talk of practicalities, which was often presented as a barrier to facilitating choice. This dilemma mirrors the current finding that professional accountability was talked about in opposition to choice, care and compassion. Perhaps over time, professional and institutional language has changed, and the way staff talk about the practicalities of their job has transformed into talk about professional accountability. The most recent previous discursive study found repertoires of ‘duty of care’ and ‘safety’ (Jingree, 2015), which seems to reflect the overarching discourse of professional accountability. Previous comparative evaluations and repertoires about ‘normalisation’ (Jingree, 2015) reflect this review’s findings that staff use comparisons to their own lives and ‘normal’ practices to account for the support they describe. The synthesis of multiple studies here suggests that these discourses are also used within the wider literature.

Care staff are integral to delivering quality services (Finlay et al., 2008) and facilitating empowerment and choice, which are central within legislative frameworks (DoH, 2009). People with learning disabilities value this critical role care staff have in their lives, and want choice, independence, good relationships and sensitive support staff (Clarkson et al., 2009; Haigh et al., 2013). Working within legal frameworks staff must be professionally accountable whilst promoting choice and empowerment. In a narrative analysis from professionals working in UK learning disability services it was found that workers felt anxious about accountability and spoke of the worst-case scenario of having to defend their practice in court (Wilson et al., 2009). It is important to notice how these concerns filter into discourse about professional accountability and could be a barrier in supporting choice and empowerment in people’s daily lives.

Clinical Implications and Future Recommendations

The current review enabled care staff discourses about day-to-day support of people with learning disabilities to be examined. The way we talk about people can impact identity, values and intentions (Jørgensen & Mølbjerg, 2006), affecting how care staff may orientate to their work, and how people with learning disabilities may experience support. Foucault suggests we are all subject to these powerful effects of discourse (Dreyfus & Rabinow, 1982). Interactions and discourses have the power to negatively impact how people with learning disabilities are constructed by themselves and others (Antaki et al., 2007; Brown et al., 2021; Scior, 2003). Thus, noticing the difficulties care staff face in negotiating talk about day-to-day support is significant as it may create a barrier for people being empowered to have choice in daily living.

Future research using discursive methodologies would be beneficial, as it enables power to be orientated to and can create awareness of discourses that perpetuate oppression (Grue, 2011). This is useful when considering marginalised groups such as people with learning disabilities, and those in roles with inherent power, such as care staff. A reflective training space for care staff could be piloted and evaluated. Within this psychoeducation could be offered to increase awareness of the impact of power and language. Care staff could be encouraged to notice and reflect on their team's dominant discourses. This discursive perspective may allow care staff and professionals to consider how discourse can constrain support. This could be evaluated to monitor any effects on how care staff orientate to supporting people with learning disabilities.

Clinical psychology has a role in supporting good community care (Kapur, 2014) and promoting wellbeing for people with learning disabilities. This requires collaboration with care staff, who may use different styles of professional talk (Kiyimba, 2015) to mental health services. Recognising differences in talk will likely aid formulating shared understandings and collaborative working. Clinical psychology should demonstrate compassion to staff stories for effective collaboration (Stenfert Kroese & Smith, 2018), which can be supported by understanding these identified dilemmas and complex positioning from discourse. The challenges in negotiating discourses around choice, care and compassion, and professional accountability could be shared with care staff. Increasing awareness of discourses may help problem-solve difficulties that arise within support and challenge these difficult discourses. This insight into the discursive context of care and support could potentially help clinical psychologists to better support care providers.

Strengths and Limitations

Discursive methodologies are rarely utilised within learning disability research; hence a systematic review of existing discourse literature on care staff support was not viable. A strength of this paper was that discursive synthesis enabled an interpretative understanding which extended the original qualitative findings. The original reported themes described the content of what care staff said, whereas this analysis demonstrated how those ways of talking were used to create meaning about people with learning disabilities. This enabled the sparse discursive literature base to be extended.

Although analysing existing data expanded discursive understanding of the area, the analysis was limited to the data quotes included in the original studies, not their entire data set. These quotes were selected by the researchers, illustrating a small proportion of collected data, and may not be representative. These may reflect the research questions or areas of interest to the researchers. None of the studies aimed to specifically explore how care staff talked about day-to-day support. Aspects you might expect, such as personal care, employment and social relationships, were rarely spoken about. Discourse analysis focuses on talk therefore the reported quotes were still meaningful as they represent language used, however it is likely that some discourses about daily living are absent within this review.

A further limitation is the broad demographics of the studies included. Studies were mostly conducted in the UK, and all the sampled countries would be considered Westernised. Discourse is situated within the particular context (Wiggins & Potter, 2017), therefore the cultural context of the sampled care settings is significant for the analysis. It could be argued there is similar historical context cross-culturally, with North America, Europe and Australasia replacing large institutions with community services for people with learning disabilities since the 2000s (Mansell, 2006). However, there may be cultural differences within ways of talk that the current analysis did not account for, as the researcher is familiar with the UK context of community care, which may have influenced analysis.

The sample also included participants with a broad range of ages and years' experience working in care. It was suggested that 67% of UK care staff for adults with learning disabilities and/or autism were 25 to 54 years old (Skills for Care, 2018). This sample likely reflects the wide range of staff usually employed within care services. However, it would be useful to comment on whether ages of participants or length of experience impacted the discourses that were employed. Staff with more care experience may perpetuate care-specific discourses, whereas newer staff may utilise wider social discourses. These subtleties were unable to be commented upon in this analysis. A further limitation is the lack of demographic information on participant ethnicity. This was reported in four studies, three of which included all white British staff. This suggests the studies are skewed towards white British care staff, but this is uncertain given the missing demographics.

Conclusion

This literature review systematically examined existing literature to identify discourses care staff used to talk about day-to-day support for people with a learning disability. The reviewed qualitative literature utilised appropriate design and methodology with rigorous data analysis, and the findings had clinical value. However, many studies were limited in adequately reporting their recruitment strategy, the researcher relationship, and ethical considerations. Within the data care staff used discursive strategies to justify the support they described and negotiated what appeared as conflict between choice, care and compassion versus professional accountability. Care staff have an integral role supporting daily living for people with learning disabilities and therefore the dominant discourses they use are important to recognise.

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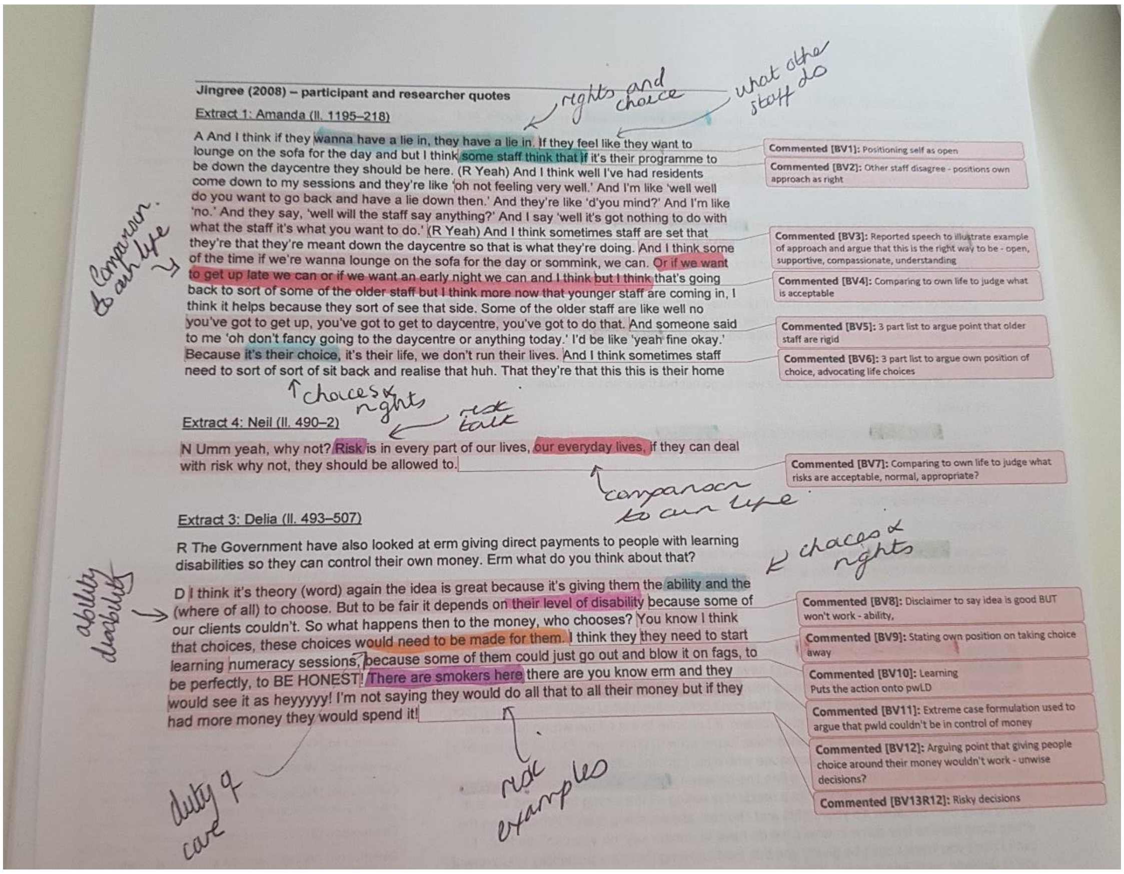
Appendix A

Extracts of Data Analysis



rights and choice

what other staff do

Jingree (2008) – participant and researcher quotes

Extract 1: Amanda (ll. 1195–218)

A And I think if they wanna have a lie in, they have a lie in. If they feel like they want to lounge on the sofa for the day and but I think some staff think that if it's their programme to be down the daycentre they should be here. (R Yeah) And I think well I've had residents come down to my sessions and they're like 'oh not feeling very well.' And I'm like 'well well do you want to go back and have a lie down then.' And they're like 'd'you mind?' And I'm like 'no.' And they say, 'well will the staff say anything?' And I say 'well it's got nothing to do with what the staff it's what you want to do.' (R Yeah) And I think sometimes staff are set that they're that they're meant down the daycentre so that is what they're doing. And I think some of the time if we're wanna lounge on the sofa for the day or sommink, we can. Or if we want to get up late we can or if we want an early night we can and I think but I think that's going back to sort of some of the older staff but I think more now that younger staff are coming in, I think it helps because they sort of see that side. Some of the older staff are like well no you've got to get up, you've got to get to daycentre, you've got to do that. And someone said to me 'oh don't fancy going to the daycentre or anything today.' I'd be like 'yeah fine okay.' Because it's their choice, it's their life, we don't run their lives. And I think sometimes staff need to sort of sort of sit back and realise that huh. That they're that this this is their home

Comparison to own life

choices & rights

Commented [BV1]: Positioning self as open

Commented [BV2]: Other staff disagree - positions own approach as right

Commented [BV3]: Reported speech to illustrate example of approach and argue that this is the right way to be - open, supportive, compassionate, understanding

Commented [BV4]: Comparing to own life to judge what is acceptable

Commented [BV5]: 3 part list to argue point that older staff are rigid

Commented [BV6]: 3 part list to argue own position of choice, advocating life choices

Extract 4: Neil (ll. 490–2)

risk talk

N Umm yeah, why not? Risk is in every part of our lives, our everyday lives, if they can deal with risk why not, they should be allowed to.

comparison to own life

Commented [BV7]: Comparing to own life to judge what risks are acceptable, normal, appropriate?

Extract 3: Delia (ll. 493–507)

R The Government have also looked at erm giving direct payments to people with learning disabilities so they can control their own money. Erm what do you think about that?

choices & rights

D I think it's theory (word) again the idea is great because it's giving them the ability and the (where of all) to choose. But to be fair it depends on their level of disability because some of our clients couldn't. So what happens then to the money, who chooses? You know I think that choices, these choices would need to be made for them. I think they they need to start learning numeracy sessions, because some of them could just go out and blow it on fags, to be perfectly, to BE HONEST! There are smokers here there are you know erm and they would see it as heyyyyy! I'm not saying they would do all that to all their money but if they had more money they would spend it!

ability disability

duty of care

risk examples

Commented [BV8]: Disclaimer to say idea is good BUT won't work - ability,

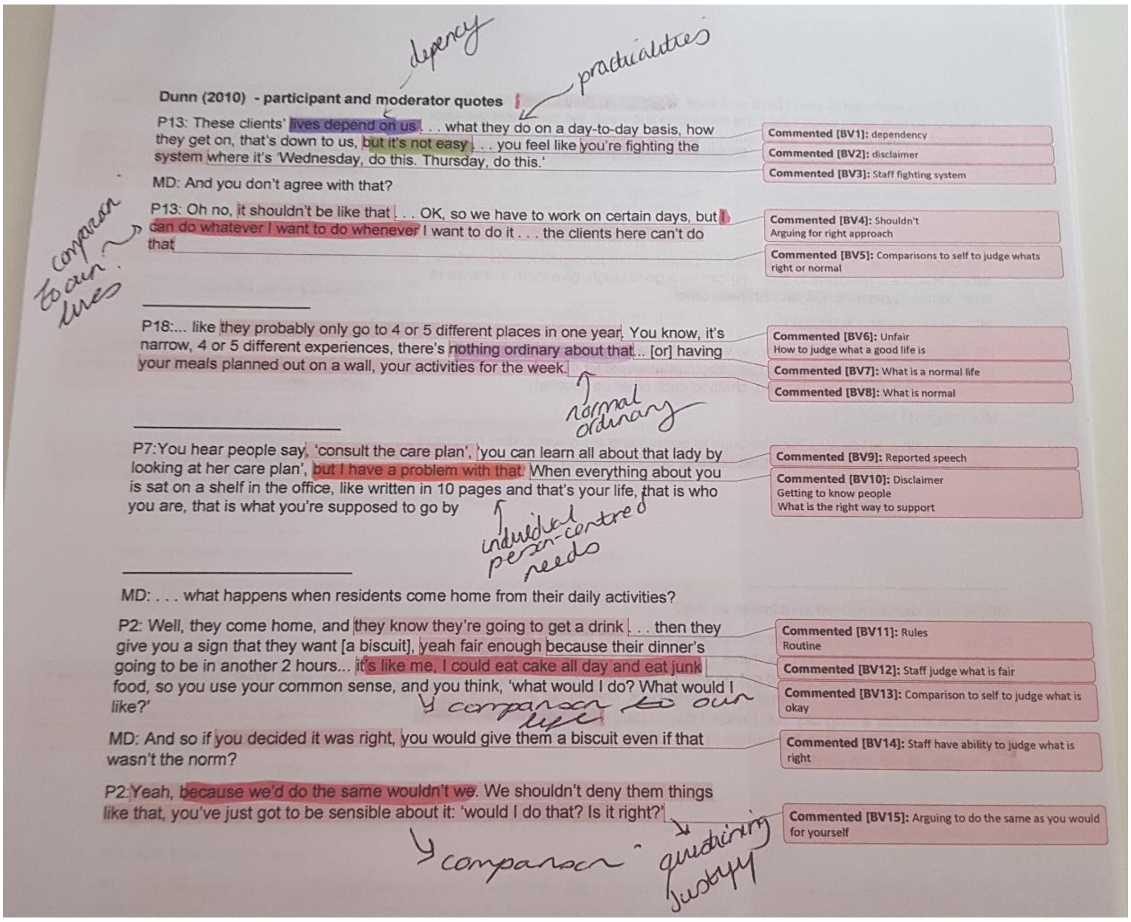
Commented [BV9]: Stating own position on taking choice away

Commented [BV10]: Learning
Puts the action onto pwLD

Commented [BV11]: Extreme case formulation used to argue that pwld couldn't be in control of money

Commented [BV12]: Arguing point that giving people choice around their money wouldn't work - unwise decisions?

Commented [BV13R12]: Risky decisions



depency

practicalities

Dunn (2010) - participant and moderator quotes

P13: These clients' lives depend on us . . . what they do on a day-to-day basis, how they get on, that's down to us, but it's not easy . . . you feel like you're fighting the system where it's 'Wednesday, do this. Thursday, do this.'

MD: And you don't agree with that?

P13: Oh no, it shouldn't be like that . . . OK, so we have to work on certain days, but I can do whatever I want to do whenever I want to do it . . . the clients here can't do that

comparison to own lives

Commented [BV1]: dependency

Commented [BV2]: disclaimer

Commented [BV3]: Staff fighting system

Commented [BV4]: Shouldn't
Arguing for right approach

Commented [BV5]: Comparisons to self to judge whats right or normal

P18:... like they probably only go to 4 or 5 different places in one year. You know, it's narrow, 4 or 5 different experiences, there's nothing ordinary about that... [or] having your meals planned out on a wall, your activities for the week.

normal ordinary

Commented [BV6]: Unfair
How to judge what a good life is

Commented [BV7]: What is a normal life

Commented [BV8]: What is normal

P7:You hear people say, 'consult the care plan', 'you can learn all about that lady by looking at her care plan', but I have a problem with that. When everything about you is sat on a shelf in the office, like written in 10 pages and that's your life, that is who you are, that is what you're supposed to go by

individual person-centred needs

Commented [BV9]: Reported speech

Commented [BV10]: Disclaimer
Getting to know people
What is the right way to support

MD: . . . what happens when residents come home from their daily activities?

P2: Well, they come home, and they know they're going to get a drink . . . then they give you a sign that they want [a biscuit], yeah fair enough because their dinner's going to be in another 2 hours... it's like me, I could eat cake all day and eat junk food, so you use your common sense, and you think, 'what would I do? What would I like?'

comparison to our life

Commented [BV11]: Rules
Routine

Commented [BV12]: Staff judge what is fair

Commented [BV13]: Comparison to self to judge what is okay

MD: And so if you decided it was right, you would give them a biscuit even if that wasn't the norm?

Commented [BV14]: Staff have ability to judge what is right

P2: Yeah, because we'd do the same wouldn't we. We shouldn't deny them things like that, you've just got to be sensible about it: 'would I do that? Is it right?'

comparison

questioning justify

Commented [BV15]: Arguing to do the same as you would for yourself

Appendix B

Identified Devices and Frequencies

Device/Strategy	Number of Quotes	Number of Studies
Care and compassion talk	24	7
Comparisons	16	5
“Happy” repertoire	13	7
Teaching and learning talk	12	3
Practicalities repertoire	11	6
Talk about choice	9	4
“Risk” repertoire	8	5
Job positioned as rewarding	8	3
Talk about people with LD’s ability	8	3
“Normal” repertoire	7	4
Infantilising positioning of people with LD	7	3
Talk about people with LD’s understanding	6	4
People with LD positioned as dependent	4	3
Duty of care repertoire	4	2
Boundaries dilemma	3	3
Other staff comparisons	2	2

Appendix C

Copy of Journal Instructions for Authors

Link to British Journal of Learning Disabilities Author Guidelines:

https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.html

SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

Care Staff Constructing the Sexuality of People with Learning Disabilities

Trainee Name:	Victoria Booth
Primary Research Supervisor:	Dr Cordet Smart Research Lead, Doctorate in Clinical Psychology
Secondary Research Supervisor:	Dr Lorna Robbins Consultant Clinical Psychologist and Clinical Lead
Target Journal:	British Journal of Learning Disabilities
Word Count:	8,366 words (excluding accessible summary, abstract, table of contents, list of figures, references, footnotes, appendices)

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter

Accessible Summary

- Everyone has the right to sex and relationships. Some people with learning disabilities want better support with this part of their lives. It is important that care staff support people in the best way.
- Care staff spoke about whether people with learning disabilities could understand sex and relationships. They also spoke about sex and relationships as risky and wanting to keep people safe. There was not much talk about sex and relationships as normal and enjoyable.
- The way staff talk about sex and relationships could change how they support people with learning disabilities. It could also change what people with learning disabilities think and feel about their sexual lives.
- It is important that sex and relationships is spoken about in a way that helps people with learning disabilities to have good lives.

Keywords: learning disabilities, sex and relationships, care staff, discourses

Abstract

Background

Everyone has the right to sex and relationships. In the past people with learning disabilities were denied these rights and continue to be dissatisfied with this area of their life. The way care staff talk about this topic impacts the people they support and their experience of sex and relationships. This study explored how care staff spoke about sexuality for people with learning disabilities.

Methods

Three care teams attended three focus groups to discuss sex and relationships for the people they support. Each group had three members of care staff and one facilitator. The data was discursively analysed.

Findings

Care staff spoke about people with learning disabilities in a way that constructed them as sexually naïve or knowledgeable. They also spoke about safety which constructed sex and relationships for people with learning disabilities as risky. These ways of talking justified the type of support they described giving.

Conclusions

Care staff used dominant discourses about sexual understanding and risk to talk about sexuality for people with learning disabilities, with normalising discourse being less common. Recognising how difficult it is to talk about this topic is important for care staff and those they support. This has implications for training and reflective sessions for care staff to better support this aspect of people’s lives.

Introduction

Sexuality is an intrinsic part of being human (The World Health Organisation [WHO], 2006), yet the sexual rights of people with learning disabilities must be promoted (Mencap, 2017). People with learning disabilities want their sexuality to be supported (Whittle & Butler, 2018), which creates an important role for the care staff supporting them. Sexuality is in part constructed through how it is spoken about, and care staff are exposed to and generate discourses about the sexual lives of those they support. Understanding these discourses, through social constructionism and discursive psychology, is integral to improving sexuality support. This introduction reviews previous literature from a discursive psychology perspective, treating knowledge as created through interaction, rather than as a fixed reality.

What is Sexuality?

Sexuality is a broad term, often used narrowly in everyday language to refer to a person's sexual orientation. Sexuality has been defined as including "sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (WHO, 2006, p. 1). Macleod and McCabe (2020) suggested sexuality is experienced and expressed through thoughts, fantasies, desires, attitudes, behaviours and relationships. When talking about people with learning disabilities, sexuality, sexual needs, and sex and relationships are used interchangeably (BILD, n.d; Mencap, 2018). This paper focuses on how care staff construct and support this aspect of people's lives; therefore, the broad umbrella term sexuality is adopted rather than a narrow definition, to allow care staff to define it within the context of support.

Social Constructionism, Learning Disability and Discourse

Misconceptions of learning disability are common and affect the daily lives of people with learning disabilities (Scior & Werner, 2015). People with learning disabilities are campaigning to challenge these societal assumptions and misconceptions, such as 'people with learning disabilities cannot get married' (n.d, Mencap). Social constructionism and discursive psychology perspectives (Jorgensen & Phillips, 2011) are used here to question this assumed knowledge about learning disability, and the category itself. The DSM-V (American Psychiatric Association, 2013) defines learning disability as an impairment in global intelligence and significantly limited adaptive functioning. Despite criticism of diagnosis and intelligence testing based on ability, learning disability as a category is considered a 'solid' construct (White, 2002). Assumptions are created through talk about people with learning disabilities (Cockain, 2014), and as talk is repeated, assumptions become treated as true. These assumptions in the category 'learning disability' can be questioned, without denying differences or diminishing the difficulties people with learning disabilities experience.

Discourse is spoken or written word that communicates our thoughts, feelings and understanding of the world, and can shape how we think, feel, talk and behave (Strauss & Feiz, 2014; Wiggins & Potter, 2017). Discourse depends on the broader social context (Dudley-Marling, 2004), and has a circular effect where people construct meaning and assumptions, which impact how others are treated, which can then perpetuate assumptions, power imbalances, inequality and dominant discourse. Using discursive psychology (Wiggins & Potter, 2017) to explore discourse can enable meanings about learning disability and sexuality to be captured, beyond assumed 'truths'.

Sexuality and Discourse for People with Learning Disabilities

The social discourses regarding sexuality and learning disabilities can be understood by locating them within the historical context. Past discourse failed to capture sexual pleasure and although care staff are more accepting towards sexuality for people with learning disabilities, services continue to be protective and risk averse, and pleasure remains absent in discourse (Bates et al., 2017; Saxe & Flanagan, 2014; Tepper, 2000; Wilson et al., 2019).

Care staff can contribute to constructing sexuality for those they care for through the discourse they use and support they provide.

The way that society historically approached the sexuality of people with learning disabilities created discourses which may be difficult for society to stop adopting. The eugenics movement caused gross abuse of people with learning disabilities through sterilization and segregation, and led to their sexuality being denied and suppressed until the 1960s (Kempton & Kahn, 1991). Sexual myths and fears were projected onto people with learning disabilities, which constructed them as asexual, salacious, innocent or deviant (Brown, 1994). From the 1980s health professionals focussed on the sexual abuse of women with learning disabilities, emphasising their vulnerability to exploitation (Bourke, 2020). This led to the accumulation of considerable evidence suggesting a higher risk of sexual abuse (Brown & Turk, 1994; McCormack, 1991; Sobsey & Doe, 1991; Stromsness, 1994; Tharinger et al., 1990). In the 1990s significant attention was given to men with learning disabilities who sexually abuse (Thompson, 2000), with researchers exploring prevalence rates, patterns of abuse and explanatory factors (O'Connor & Rose, 1998).

These historic perceptions have influenced the way services for people with learning disabilities were organised, either following ‘innocence’ models protecting people from the public, or ‘degenerate’ models protecting the public from them (Brown, 1994). Whilst public discourse focussed on deviance, abuse and asexuality, discourses on pleasure were absent (Tepper, 2000). This was reflected in wider social discourse which focused on risk and sexual health, but has since shifted towards acknowledging the positive impact of pleasurable, fulfilling sexual experiences for people without a learning disability (Anderson, 2013). This change in discourse is not notable for people with learning disabilities, with sexual identity, pleasure or desire being rarely spoken about (Wilson et al., 2019).

Another area of notable absence are the experiences of LGBTQ (lesbian, gay, bisexual, transgender, or queer or questioning) people with learning disabilities, with no published research prior to 2001 (Abbott, 2015). A pilot study on learning disability staff training found heterosexist and homophobic attitudes during discussions, and that LGB people with learning disabilities face double discrimination (Abbott & Howarth, 2003). In 2005, staff in learning disability services identified sexuality related bullying and discrimination in the lives of LGB people with learning disabilities (Abbott, 2015). A recent Swedish study found that healthcare professionals described heteronormative treatment for people with learning disabilities, and those with other identities were largely invisible (Sommarö et al., 2020). LGBTQ people with learning disabilities therefore seem to face additional and unique experiences of discrimination and oppression due to the intersectionality of disability and sexuality.

A recent study explored the intersectionality of age, disability and sexual identity for young, disabled people who identified as LGBT+ (Toft et al., 2020). Their stories included the theme incapability, which was underlined by conceptions of people with disabilities as incapable of being LGBT+ (Toft et al., 2020). There was also a theme of delegitimization where disability rendered sexuality as not legitimate due to desexualisation (Toft et al., 2020). Another study explored the lived experiences of LGBT people with learning disabilities, identifying that others problematised and denied their sexuality as others believed they were unable to know their own mind (Dinwoodie et al., 2020). Some participants experienced only partial support for their learning disability or sexuality needs, but not inclusive support (Dinwoodie et al., 2020). Discourses of capability seem prevalent for LGBTQ people with learning disabilities, with implications for their experience of support and discrimination.

Sexuality is constructed through social interaction, requiring safe and positive experiences without discrimination (WHO, 2010), and people with learning disabilities are dissatisfied with their experiences. A systematic review of 14 studies found that people with learning disabilities wanted an intimate relationship but were concerned about restrictions, rules and being reprimanded by caregivers (English et al., 2018). A meta-synthesis of 16 studies also found that people with learning disabilities desired intimacy, friends, pleasure and for their sexual identity to be recognised (Black & Kammes, 2019). Yet, those sampled felt that others controlled and regulated their sexual experiences and that they had no power to express their sexuality (Black & Kammes, 2019). The systemic context and social interactions people experience are significant in constructing and expressing sexuality.

Sexuality can be profoundly shaped by social norms (Lorimer et al., 2019), which are what is commonly done (normal), and what is commonly approved of (socially sanctioned) (Cialdini et al., 1991). Given the historical context there may be different social norms around sexuality for people with and without learning disabilities. A meta-ethnographic synthesis of 16 studies of people with learning disabilities' experiences found that people felt a conflict between social norms to limit their sexuality, and their internal sexual desires, and often distanced themselves from their sexuality (Whittle & Butler, 2018). Social norms thus have a significant impact on the construction and expression of people's sexuality.

For people living in residential or supported living homes, care staff contribute to the social norms and context that develop a person's sexual identity. Opportunities to make decisions and develop relationships also support the healthy development of sexual identity (Ailey et al., 2003), yet a lack of privacy, social opportunities and sex education are barriers for people with learning disabilities (Mencap, 2018). Many do not have opportunities or support to develop and maintain meaningful relationships (Wilson et al., 2019). Care staff who can enable privacy, social inclusion and meaningful relationships hold a significant role in supporting sexuality.

The Role of Staff Discourse

Care staff significantly contribute to the social world of people with learning disabilities, and are generally positive, moderately liberal, and accepting towards sexuality for people with learning disabilities (Bazzo et al., 2007; Cuskelly & Bryde, 2004; Evans et al., 2009; Meaney-Tavares & Gavidia-Payne, 2012; Saxe & Flanagan, 2014). However, people with learning disabilities think that excessive rules and restrictions are placed on their sexual behaviour and express dissatisfactory support of sexuality (Brown & McCann, 2018; Fitzgerald & Withers, 2011; Healy et al., 2009; Hollomotz, 2008; Whittle & Butler, 2018).

Focus on vulnerability and risk continue to impact current discourse and the contradictory practices that are seen in support services, with a culture of ‘protectionism’ and ‘risk aversion’ which restrict sexual expression (Bates et al., 2017). The limited discursive research on staff talking about sexuality for people with learning disabilities identified discourses of control, risk, and protection (Brown & McCann, 2019; Pariseau-Legault et al., 2019; Winges-Yanez, 2014). Being regulated, controlled, and infantilised affected women with learning disabilities’ perceptions of themselves as sexually passive (Fitzgerald & Withers, 2011). This suggests discourses continue to reflect past assumptions which oppress sexuality and neglect sexual wellbeing and pleasure.

The way care staff talk about sexuality can impact the way people with learning disabilities interpret and respond to support and discourses. Grace et al. (2017) identified staff discourses about protection, conditional permissions, staffs’ position of authority and withholding understanding from people with learning disabilities. These discourses not only constructed a context of uncertainty or protection in the support of sexuality, but generated discourses of acceptance or resistance from residents (Grace et al., 2017). This research was conducted in a secure hospital for people with mental health and offending needs which could account for staff talking about protection, rules and authority. The findings that residents resisted or accepted these discourses may have different meaning in this setting. However, it is cautiously suggested this demonstrates how staff discourse can impact meaning for people with learning disabilities and how they respond.

There is limited research directly exploring staff discourse on supporting sexuality. Hamilton (2009) outlined two support workers talking about the relationship between people with learning disabilities who live in a residential home. The support staff spoke about sexuality using concepts such as capacity, being knowledgeable and normal sexual behaviour, which informed how as support staff they responded (Hamilton, 2009). The study does not detail the rigour of the analyses and presents few extracts, making the credibility difficult to determine, but does demonstrate discourses used by care staff to discuss sexuality for people with learning disabilities.

Winges-Yanez (2014) shared their past experiences of sexuality for people with learning disabilities living in residential settings, using autoethnography to consider the dominant discourses. The approach relied on author recollection but stated their position and outlined the process, demonstrating transparency. The author noticed discourses centred on control, judgement, protection and paternalism, and an absence of discussions about sexual expression and identity. It is suggested that although residential settings may have policies that address sexuality and the law, staff training might enable the support of healthy sexual expression for people with learning disabilities (Winges-Yanez, 2014).

In a recent study support workers believed there was a lack of clear organisational policies and were concerned about accountability when supporting sexuality for people with learning disabilities (Pariseau-Legault et al., 2019). There were contradictory discourses about promoting choice and autonomy but also managing risk and best interests (Pariseau-

Legault et al., 2019), which created a dilemma, demonstrating the complex landscape staff must navigate in their role when talking about and supporting sexuality.

A recent narrative review of the literature explored the views of families and direct care support workers about the expression of sexuality by people with learning disabilities (Brown & McCann, 2019). Families and care staff were concerned about risk of sexual exploitation, and maintaining control was seen as important to protect people from harm. There was a dilemma between recognising sexual rights and needs, versus exploitation and abuse (Brown & McCann, 2019). This demonstrates how vulnerability continues to be a dominant discourse that impacts the way staff talk about sexuality.

Aim and Research Question

Given the need to offer better sexuality support to people with learning disabilities, and understanding this as socially constructed in part through how it is spoken about, this study aimed to explore care staff discourse on supporting sexuality. UK residential care staff talk will be examined to answer the following research question;

What discourses are used by care staff to describe and construct sexuality for people with learning disabilities?

Method

Design

A cross-sectional focus group design was used to identify sexuality discourses that care staff used when talking about people with learning disabilities.

User Consultation

Three people with learning disabilities supported by two different care providers agreed to user consultation. They were consulted individually using a semi-structured interview (Appendix F) and key themes were identified from these discussions; the barriers for people accessing sex and relationships, the importance of staff support, feeling comfortable speaking to staff about support needs and the question about responsibility to initiate these conversations. These key ideas were included in the focus group interview (Appendix G).

Data Collection

NHS learning disability teams sent recruitment information (Appendix D) to local care providers and 17 residential/supported living services were directly contacted. Any member of care staff proving support for people with learning disabilities in a residential/supported living service were eligible. Three focus groups were conducted, each with three members from the same support team which included direct support workers, team leaders and home managers.

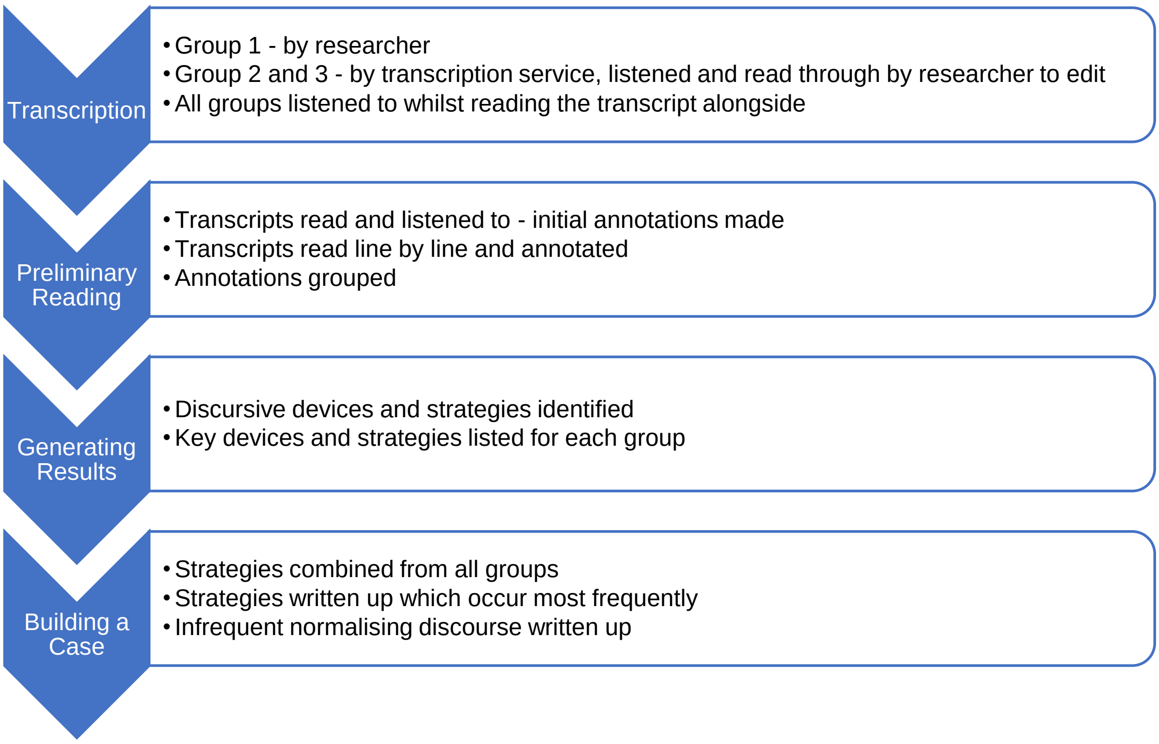
Focus groups lasted approximately one hour via video call and were recorded. The purpose of the group was introduced, it was confirmed that participants understood the information sheet and there was an opportunity for further questions. The limits to confidentiality were explained, individual views were requested to be kept confidential and everyone was encouraged to contribute and share different views. The participants were then asked to discuss together sexuality for people with learning disabilities and their support role. The follow-up questions from the interview schedule (see Appendix G) were used as prompts when the conversation stopped, or certain areas were not covered in the discussion. Afterwards, participants reflected on the group process and were encouraged to contact the research team individually for support if needed. Resources on sex and relationships for people with learning disabilities were provided to staff and the care homes who participated.

Method of Analysis

The researcher transcribed a third of the data verbatim and edited the externally transcribed data to ensure accuracy and familiarity with all groups. The analysis process was informed by Goodman (2017) (detailed in Figure 1). The data was read and reread to identify the action orientation relevant to the research question and the discursive devices used: subject positions, repertoires and ideological dilemmas. Subject positions are the ways that people are located through talk, repertoires are a repeated way of talking about something which categorises it in a form that is culturally understandable, and ideological dilemmas are opposing ways of understanding the same concept (Wiggins & Potter, 2017).

Figure 1

Data Analysis Process



Credibility

Considering credibility, the data were taken to discourse analysis groups to gain other perspectives and were discussed regularly in research supervision. A bracketing interview was completed with the field supervisor to aid reflexivity (Rolls & Relf, 2016; Tufford & Newman, 2010) and a reflective journal was kept throughout the research process (Extract in Appendix I). The data analysis process is outlined, and extracts of data analysis are shown in Appendix H to demonstrate transparency.

Reflexivity

I am closely positioned to the topic due to personal and professional experiences with people with learning disabilities and care staff. In a bracketing interview I explored being a sister, previous support worker, psychology professional and white heterosexual British woman in my late 20s. I reflected on care plans I have suggested to support people's sexuality and noticed preconceptions of care staff not actively supporting this from my professional experiences. I also related to uncomfortable feelings about supporting sexuality from my personal experiences. During the research process I tried to consider how I may judge supporting sexuality as proactive or reactive but may empathise with staff finding it uncomfortable.

Ethical Considerations

Ethical approval (reference eCLESPsy002004) was given by Exeter University (Appendix A). Care managers were approached to discuss the research project and sent the Participant Information Sheet (Appendix B) to care staff within their organisation. All staff had the opportunity to discuss the study with the researcher. Participants were fully informed about the nature of the study, what participation would involve, how their data would be stored and used, and provided informed consent (Appendix C). The facilitator encouraged acceptance of others' views and acknowledged it may have been an uncomfortable or difficult discussion, reiterating that individuals could contact separately to discuss anything further. A copy of the confidentiality agreement that transcriptionists signed before being employed by Devon Transcription is included in Appendix L.

Focus Groups

All names and identifying information have been changed to protect individual and organisation identity (see Table 1). The original line numbers were included to demonstrate their location in the transcript and were coded as (X).

Table 1

Participant and Care Team Pseudonyms

Care Team	Staff Name	Staff Role
Chaffinch	Emily	Support worker
	Peter	Support worker
	Gary	Support worker
Nuthatch	Maria	Care home manager
	Pippa	Team leader
	Betty	Support worker
Skylark	Susie	Care home manager
	Laura	Deputy manager
	Carrie	New support worker

Analysis

This research aimed to explore how care staff constructed sexuality for people with learning disabilities. The findings are organised within three main facets. Firstly, people with learning disabilities were positioned as *sexually naïve or knowledgeable.* Secondly, discourses invoked when discussing sexuality focused on *risk and safety.* These ways of talking constructed a role for staff in managing people with learning disabilities' sexual lives. Lastly, the infrequently adopted *normalising discourse* was an uncommon but possible way of talking. Each of these points is discussed here in turn, using eight extracts.

Sexually Naïve or Knowledgeable

People with learning disabilities were positioned in terms of their sexuality at times as adults and at other times their understanding was questioned. On occasions a specific dilemma was evident where these discourses came together, and staff struggled with whether people with learning disabilities were knowledgeable or naïve in their sexual understanding. These positions justified the type of support staff described offering.

'They are Adults': a Repertoire

Participants repeatedly stated that people with learning disabilities *'are adults'*, seemingly forming a discursive repertoire. This repertoire argued that people with learning disabilities *'are adults',* although the need for assertion suggested this categorisation may not always be accepted. This was demonstrated within Extract 1.

Extract 1: Chaffinch 3 minutes into discussion.

The Chaffinch team began their discussion talking about sex and relationships for a service user named Freddie:

31 ***Peter:*** *cos like Emily says it does get brought*
32 *up quite often um little comments here little comments there but um I don't shy away from*
33 *them conversations um I don't actively promote them I don't start these conversations but I*
34 *certainly don't shut the conversations down either I um I roll with it and yeah just he is an*
35 *adult and this is what we have all got to remember he's an adult so it's not as if I've got my*
36 *12 year old son here you know [laugh] being inappropriate and asking leading questions*
37 *as far as relationships are concerned but no he's an adult and [over speaking]*

Peter positioned himself with the power to *'shut down conversations'* (34) and the moral authority to judge what was appropriate and inappropriate. This positioned care staff as managing sex and relationships for people with learning disabilities, and people with learning disabilities as needing managing. It also categorised appropriate and inappropriate as constructs which can be differentiated for sexuality. Peter repeated *'he is an adult'* (34), suggesting that Freddie being an adult was something that needed stating and could be questioned. Peter then used a comparison of his 12-year-old son to seemingly reaffirm that Freddie is an adult (35).

Naïve in Sexual Understanding

The following extracts from the Skylark team discussion demonstrate how staff talk about people with learning disabilities' understanding of sex and relationships, which at times constructed them as naïve in their sexual understanding and positioned staff as needing to protect them.

Extract 2: Skylark 22 minutes into discussion.

380 ***Laura:*** *no oh no no no no [over speaking]*
381 ***Susie:*** *not unless they've seeked it from us I suppose or if we've seen signs [over speaking]*
382 – 384 omitted for brevity
385 ***Susie:*** *we've got quite a a mixed bunch here so we've got some individuals that have no*
386 *capacity whatsoever erm and we've got some that have a lot of capacity [over speaking]*
387 ***Laura:*** *full full capacity in all areas*
388 ***Susie:*** *so the guys that have full capacity it's a very open subject but there are*
389 *individuals that haven't got capacity erm I mean putting it bluntly they wouldn't*
390 *understand what we were saying to them erm so in that case no we haven't*

When asked if anyone had introduced the topic to someone with learning disabilities, the repeated *'no'* from Laura (380) conveyed that this would be highly inappropriate. Susie elaborated that they would only talk about sex and relationships if the person asked, or they saw 'signs' or 'behaviours', constructing sexuality as only relevant for some people, and thus impacting how staff talk about offering support.

Susie then elaborated that some people in the home have *'full capacity'* (388), whilst others *'haven't got capacity'* and *'wouldn't understand'*. This constructed capacity on a continuum and staff as able to determine 'how much' capacity someone has. People with learning disabilities were positioned on this capacity continuum as being able or unable to understand sex and relationships. This constructed sexuality as interlinked with one's ability ‘to understand’ and presented people as either sexually naïve or knowledgeable. This is extended upon in Extract 3.

Extract 3: Skylark 30 minutes into discussion.

The Skylark team were talking about a person living in their care home who visits cities independently and suggest that he was not taught about sex and relationships, making him vulnerable.

520 ***Laura:*** *even even basic things like if they you know if if you do want to have sex this is*
521 *how you have sex safely*
522 ***Susie:*** *yes*
523 ***Laura:*** *this is how you consent to sex this is how you you do not consent to sex this is the*
524 *areas you know and and what is acceptable and what’s not acceptable for how people*
525 *treat* **you** *sexually as well which I don’t think he would understand at all*

Through the discussion people with learning disabilities were constructed as not understanding *‘basic things’* (520) about sex and relationships, including *‘how you have sex safely’* (521) and *‘what is acceptable’* (524). This constructed sex and relationships as either acceptable and safe, or unacceptable and unsafe. This demonstrates the social influence of what is ‘acceptable’ sexually within societal norms. It positioned staff as having this knowledge and the moral authority to determine what is appropriate, and judge whether someone with learning disabilities understands this construction.

Constructing Sexuality: a Dilemma

The repertoire *‘they are adults’* and talk about sexual understanding resulted in a dilemma between constructing sexuality for people with learning disabilities as child-like, innocent and lacking understanding, or being *‘adult’*, knowledgeable and private about their sex lives. This is illustrated in the following extracts from the Chaffinch team discussions where Freddie and Matthew, two service users, were compared.

Extract 4: Chaffinch 19 minutes into discussion.

279 ***Peter:*** *well Freddie's more like like a child really in he a child's mind [over speaking,*
280 *inaudible] whereas Matthew's more a closed book*
281 ***Emily:*** *yeah and I think Matthews's um very um sneaky I think he would*
282 ***Peter:*** *yeah that's that's probably that's a great word to use to describe him really*
283 ***Emily****: yeah yeah and he'll [over speaking]*
284 ***Peter:*** *and although there's nothing wrong with what he's doing you know what I mean*
285 *but he's still he's got that adult head of "all right that's my business" do you know what I*
286 *mean*
287 ***Emily:*** *yeah*

(lines 288- 322 removed for brevity)

322 ***Emily:*** *but Freddie is a lot more naïve about it than Matthew I think he's a little bit more*
323 *um um like you said he's more of a more of a child about it in his brain he's [over speaking]*

Freddie was compared to *'more like a child really'* (279) which constructed him as naïve and innocent, whereas Matthew was described as '*sneaky'* and '*a closed book'* (280), constructing his sexuality as knowledgeable and private. These contrasting descriptions generated a consensus within the group, creating the sexuality of people with learning disabilities as naïve or knowledgeable. The disclaimer *'although there's nothing wrong with'* (284) questioned whether people with learning disabilities being private about their sex lives was something that could be constructed as wrong. Following the disclaimer Matthew was compared to an adult, *'he's got that adult head of'* (285) and reported speech references Matthew knowing his right to privacy, suggesting this was unusual.

Freddie was described as *'a lot more naïve'* (322) than Matthew, maintaining the positioning of people with learning disabilities as sexually naïve or knowledgeable. The suggestion that he is a child *'in his brain'* (323) constructed this identity as inherent and biological. This demonstrates the powerful historical and medicalised discourse of people with learning disabilities as eternal children, and how this continues to influence the construction of peoples' identity. Later in the conversation, Emily says '*and I mean he's a fully grown man'* which further shows the biological and child discourses that construct sexual identity for people with learning disabilities.

Risk and Safety

The following extracts demonstrate the difficult negotiations staff face when discussing day-to-day aspects of sexuality for people with learning disabilities, such as masturbation and pornography. Sexual needs were spoken about using contrasting repertoires of risky or safe, healthy or unhealthy, and right or wrong; constructing sex as inherently dangerous and needing to be made safe for people with learning disabilities. This is demonstrated within extracts about '*needing to be safe'*, and a discussion about '*the right kind of pornography'.*

Needing to be Safe

Talk about sexual behaviours such as masturbation, alongside repertoires of safety, risk assessment and capacity, are shown in the extracts below.

Extract 5: Skylark 10 minutes into discussion.

197 ***Laura:*** *we've also had another incident well not an incident as*
198 *such there was a a gentleman here who does lack capacity who was masturbating*
199 *err in the shower erm and we had two staff members come to us I think one dealt*
200 *with it very well erm in the sense of they said "right that that's fine you're you're*
201 *doing that I'm going to make sure you're safe and well and I'm going to leave the*
202 *room and give you some privacy" whereas I do know another staff member had*
203 *actually said to him "do not do that while I am here" rather than explaining in full and*
204 *I think that the staff is what we're trying educate them is none of the behaviours are*

205 *wrong erm but they do have to be fully explained and you know risks have to be*
206 *weighed up and time given really*

Laura spoke about a resident with learning disabilities masturbating in the shower (198), referring to masturbation as an *'incident'* (197) and associating sex with risk. The idea that someone can *'lack capacity'* (198) was introduced as a solid concept that categorised the person and demonstrated knowledge about laws and procedures. The example was used to demonstrate right and wrong responses to masturbation and positioned the speaker as having the moral authority to judge this. Stating that *'none of the behaviours are wrong'* (204) suggested this can be questioned; some sexual behaviours are constructed as wrong. Laura's assessment of masturbation as not *'wrong'* but needing a risk assessment positioned her as open and supportive, and sex as risky.

207 ***Susie:*** *yeah and as Laura said this individual really does lack capacity he he requires*
208 *our support for every need that he has erm obviously apart from that [laughs] but he*
209 *but as Laura said it's educating the staff to I think there was this culture where people*
210 *with learning disabilities didn't do anything like that they didn't have sex they didn't*
211 *masturbate they didn't have these thoughts and actually they're human beings just*
212 *like we are they have [over speaking]*

Susie upgraded Laura's assessment by stating that the person with learning disabilities *'really'* lacks capacity (207), positioning capacity on a continuum. The professional language of capacity seemed to legitimise how much support someone needs and positioned staff as able to determine this. Susie introduced historical context (210) which contrasted previous perceptions of people with learning disabilities and sex and positioned herself as more open. The group then reached a consensus that people with learning disabilities have sexual needs, likening these to their own experiences *'just like we are'* (212).

213 ***Laura:*** *they're pleasure seekers*

214 ***Susie:*** *they're pleasure seekers and they have needs and they desires and you know if*
215 *they want to do that they can do that but like Laura said it's about managing it and*
216 *and educating the staff that actually it's okay for them to do that you just need to*
217 *leave them to it make sure they're safe and give them their privacy*
218 ***Carrie:*** *yeah*

The descriptor *'pleasure seekers'* evoked the similar phrase 'thrill seekers', which introduced the concept of danger. Talk of people being *'safe'* (217) constructed sex as unsafe if staff were not *'managing it'* (215). This built a strong argument for staff having a role supporting sex and relationships for people with learning disabilities.

Right Kind of Pornography

The Chaffinch team discussed the *'right kind of pornography'* which constructed the sexual lives of people with learning disabilities as either 'wrong' or 'right':

Extract 6: Chaffinch 23 minutes into discussion.

Emily stated that Freddie has *'an unhealthy relationship with sex'* (341) due to not understanding sex and being restricted from watching pornography by parental controls on his internet. This led to the below discussion about Freddie watching pornography.

349 ***Peter:*** *yeah huh I mean I get the predicament they're in though if I'm brutally honest it's*
350 *kind of I mean I'm I'm probably more pro towards sort of book format for Freddie*
351 *because I just don't want him to get the wrong idea about relationships because unless*
352 *you've got the right kind of pornography pornography in general is a real unhealthy*
353 *unrealistic way of looking at sex so I don't think for one minute that watching porn for*
354 *Freddie would be the right way about it I think book format and I don't know whether there*
355 *is any kind of soft porn films but I think that would be the direction I would [over speaking]*
356 ***Emily:*** *you're right yeah*

Peter stated *'I just don't want him to get the wrong idea'* (351) about relationships from pornography; constructing sex and relationships as synonymous for people with learning disabilities. This blocked the idea that people with learning disabilities could have sex without a healthy relationship. The use of *'just'* (351) minimised the restriction, and the *'right kind of pornography'* (352) positioned Peter as not wanting to deny Freddie pornography but manage what pornography he views. The assessment suggested a right and wrong way for Freddie to be sexual and positioned staff as accountable for ensuring it is the right way. This presented staff as having a moral duty to ensure people with learning disabilities have the 'right' sexuality.

357 ***Gary:*** *sorry Peter what do you mean by book format [pause] like magazines or [over speaking]*
358 ***Emily:*** *magazines [over speaking]*
359 ***Peter:*** *yeah I suppose yeah*
360 ***Emily:*** *magazines or*
361 ***Gary:*** *so photos*
362 ***Peter:*** *I expect if you look deeply on the internet I spect there is magazines specifically*
363 *targeted for people with learning difficulties and and if and if there isn't there should be*
364 *really*
365 **Gary***: yeah but at the same time all due respect it's like our own sexual er shall we say*
366 *appetite is [over speaking]*
367 ***Peter:*** *it's subjective in it [over speaking]*
368 ***Gary:*** *it's all very different*
369 ***Peter:*** *yeah*

Gary queried Peter (357), which interrupted the assessment of a *'right kind of pornography'* and disrupted the consensus, highlighting the complexity of the discussion.

Peter used categorisation (363) to suggest specific pornography, adding to the construction of a ‘*right kind of pornography’* for people with learning disabilities. Gary suggested that everyone has their own sexual preferences (370) which normalised sex for people with learning disabilities.

370 ***Gary:*** *everyone has their own little kinks and curiosity so I think if we were to try and find*
371 *like a [pause] like a blander version of it it might not suit him but it's still worth a try*
372 *because we need to go down those avenues but I think it's almost like we're restricting*
373 *what he's been seeing as well so we're giving him a regulated version of what we think is*
374 *acceptable*

Gary continued to normalise different sexual preferences (370) and used hedging to negotiate the disagreement delicately. Gary tentatively suggested *‘it’s almost like we’re restricting him’* (372) which gently challenged the use of control and management of sex and relationships to align with what staff judge as acceptable. This questioned if people with learning disabilities need to have acceptable sex and relationships, and if staff have the moral authority to make these decisions.

375 **Peter:** *yeah but that’s [over speaking]*
376 **Emily:** *like Peter said with the more hardcore stuff it would give him an unhealthy erm*
377 *attitude towards it and I think [over speaking]*
378 **Peter:** *and that’s that's the beauty of being where we are because we can control what we*
379 *feel is healthy for this specific person in question erm like say I get what you mean everyone*
380 *is into different things but I would feel a lot more comfortable handing over Freddie some*
381 *soft romantic pornography rather than giving him a DVD of hardcore porn do you know*
382 *what I mean if it's one or the other I know exactly what I’m going to give to him [over*
383 *speaking, inaudible] and say “oh give this a watch” [over speaking]*

Peter and Emily disagreed and reiterated the risk of pornography giving Freddie an *'unhealthy attitude'* (376) towards sex. This constructed people with learning disabilities as unable to control their own sexual desires and positioned staff as needing to control this. Peter assessed staff being able to control sex and relationships as positive (378) and used the contrast of giving Freddie '*hardcore porn'* versus '*soft romantic pornography'* to reiterate risk (381). This talk demonstrated the difficulty staff have in moving away from the construction of sex and relationships as either 'right' or 'wrong' for people with learning disabilities. Discourses about risk and unhealthy attitudes developed the argument for staff needing to manage this aspect of people's lives, which were difficult for staff to challenge.

Normalising Sex and Relationships

Within the groups there were times, although infrequent, when sexual orientation was talked about, which normalised sex and relationships within the talk as these discourses reflected wider social discourses on sexual preferences.

Extract 7: Chaffinch 58 minutes into discussion

937 **Gary:** *yeah just you know just saying basically like I think there's a there's a question mark*
938 *I mean I wouldn't if someone said to me "what sexuality would you say Freddie is" I'd*
939 *have to say "not sure" yeah*

940 ***Peter:*** *oh really*

941 ***Emily:*** *yeah I'm [over speaking] [inaudible]*

At the end of Chaffinch's team discussion Gary questioned what sexual orientation Freddie might be (937), which normalised sexuality for people with learning disabilities. Gary described situations which made him unsure of Freddie's sexual orientation, but the conversation was not elaborated upon by the group. This may be because it was towards the end of the group and the conversation got cut short. However, it was not introduced until later, which could be because these normalising discourses about sexual orientation for people with learning disabilities are not readily available within society.

Extract 8: Nuthatch 19 minutes into discussion

When the Nuthatch team were asked whether they had ever introduced the topic of sex and relationships into conversation with a person with learning disabilities they initially said no, then Betty remembered a time when Pippa asked a service user named Sophie about her sexual orientation (222).

222 **Betty:** *oh there was that time when um you were doing that form with Sophie someone we*
223 *support and um you know you said to her "do you like men or do you like women" and*
224 *like because that was what the question was asking "what is your sexuality" and she said*
225 *"oh no I like men you know definitely" so that is a conversation we have had before we*
226 *haven't induced it but*
227 **Pippa:** *of course yes that was when we were filling out um the census um form online and*
228 *I was involving the person who it was about and I was going through the questions with*
229 *her and she was answering them we come to that question and she first of all said "both"*
230 *and then she realised what the question was and er because I put it in a different way I*
231 *said "are you attracted do you fancy men or women" and she was like "oh definitely*
232 *definitely men girls are pretty but men I like men" um so yes that was yeah that was me I*
233 *initiated that question yeah*

Pippa elaborated and used reported speech to demonstrate how she changed the phrasing of the question to find out whether Sophie was attracted to men or women (231). This normalised different sexual orientations for people with learning disabilities, although does not reflect wider social discourses about sexual identity which may not only include heterosexuality or homosexuality.

Discussion

This study explored how care staff constructed sexuality for people with learning disabilities, revealing dominant discourses of risk and safety, and a dilemma between positioning people as sexually naïve or knowledgeable. These ways of talking often justified the type of support staff described providing. It was difficult to normalise sexuality when talking, which occurred at times, but was overshadowed by more dominant discourses.

This study extends previous findings that staff used a knowing/clueless binary which often positioned staff as ‘knowing’ and people with learning disabilities as ‘clueless’ when talking about sexuality (Hamilton, 2008). The current study demonstrates that care staff further negotiate whether people with learning disabilities themselves are knowledgeable or naïve. This dilemma was navigated using the repertoire ‘they are adults’ and talking about ‘capacity’, which made the type of support seem acceptable based on the person’s assumed understanding of sex and relationships. This supports previous evidence that care staff discuss ‘being knowledgeable’ and sexual ability in relation to capacity, to justify offering support (Hamilton, 2009). People with learning disabilities want to be treated as adults (Hollomotz, 2008), but knowledgeable and naïve discourses make it difficult to talk about people with learning disabilities as sexual adults.

Within the groups sex was positioned as risky or safe, healthy or unhealthy, and right or wrong. This constructed sex as dangerous and needing to be made safe, which aligned with Pariseau-Legault et al. (2019) who found contradictory staff discourses where sexual needs were placed in opposition to risk. Risk legitimised the role care staff have in managing this aspect of people’s lives, which reflects previous findings that care staff think controlling sex and relationships is important to manage risk and harm (Brown & McCann, 2019).When sexuality is constructed as a risk this can become internalised by support workers and influence ethical decisions (Pariseau-Legault et al., 2019). Understanding this potential impact of risk discourse is important for supporting sexuality for people with learning disabilities.

Care staff must work within complex legal frameworks to support wellbeing whilst protecting people from harm, and fear accountability and blame (Bates et al., 2020; Rushbrooke et al., 2014). Legislation gives people with learning disabilities the right to respect for private, home and family life (Human Rights Act, 1998), for their individual wellbeing to be promoted (Care Act, 2014), and for treatment to be free from discrimination (Equality Act, 2010). Care staff must assume people have capacity, and if established to lack capacity act the least restrictively in the individual's best interests (Mental Capacity Act, 2005). Care staff must also ensure they safeguard those they support from forms of abuse, including sexual and psychological (Care Act, 2014). These complex parameters likely influence discourses of risk, safety and capacity, and may make it difficult to challenge these dominant discourses.

Within the data there was little discussion about LGBT people with learning disabilities, therefore it could not be determined if incapability and delegitimization stories (Toft et al., 2020) were perpetuated through discourse. The limited reference to sexual orientation seems to maintain the invisibility of LGBT people with learning disabilities and heteronormative approach to sexuality (Sommarö et al., 2020). This reiterates that LGBT people with learning disabilities face significant challenges with their sexual expression and identity (McCann et al., 2016) due to the intersectionality of disability and sexuality.

Normalising discourses about sexual preferences, identity or needs were also less frequently observed in the data. This is in line with research demonstrating that sexuality for people with learning disabilities is not viewed as a holistic need about love, pleasure, desire and identity (Wilson et al., 2019). The focus on talk about risk and lack of positive discourses mirrors general sexuality discourse found within social care (Dodd & Tolman, 2017). Pleasure and normalising sexuality seem to continue to be notably absent within discourse.

The absence of pleasure when talking about sexuality for people with learning disabilities may impact how people view their sexual selves. Bernert and Ogletree (2013) interviewed women about their perceptions of sex and found that only two out of 14 women associated sex with pleasure. In another study women spoke about restrictions on their sexual behaviours, perceived sex as bad and did not have positive sexual identities (Fitzgerald & Withers, 2011). A synthesis of qualitative literature revealed how people with learning disabilities tended to distance themselves from their own sexuality (Whittle & Butler, 2018). Therefore, how sexuality is spoken about can impact not only how care staff support sexuality, but how sexual identity is developed and expressed by people with learning disabilities.

Clinical Implications and Future Recommendations

People with learning disabilities desire sexual relationships but report barriers and restrictions to expressing their sexuality (Black & Kammes, 2019; English et al., 2018). The way people talk about a topic can impact behaviour and interaction (Strauss & Feiz, 2014), therefore discourse could impact how sexuality is supported. Support can positively or negatively influence people’s experience of the world, the construction of their identity, and their sexual expression (Fitzgerald & Withers, 2011; Healy et al., 2009). Thus, discourse has the potential to impact how care staff talk about and support sexuality, and how people with learning disabilities experience this support. Understanding care staff discourse therefore has systemic implications for improving sexuality support through challenging constraining discourses.

Care staff training and reflective sessions could be developed using the identified discourses. Support workers want and need access to sexuality training and reflective practice to better support sexuality for people with learning disabilities (Maguire et al., 2019). Good practice guidelines have been developed for clinical psychologists supporting care staff, which include normalising sexual expression, understanding the law and balancing rights and protection (English et al., 2020). Including the current findings on difficulties navigating risk and safety discourses, dilemmas about sexual understanding, and lack of normalising discourse could support reflection for care staff. These sessions could be evaluated to assess whether sharing and reflecting on difficult discourses impacts care staff supporting sexuality.

Future research could identify dominant discourses used by care staff, and then share these discursive findings with participants to monitor if this impacts further discourse. This would increase understanding of whether alternative discourses can be negotiated within the difficult parameters care staff work within. There is previous evidence that staff teams can benefit from discussing their own conversations (Smart et al., 2018), which suggests that helping staff to notice and reflect on their discourses may be useful. Further studies could help staff to notice the discursive strategies they employ and observe the impact this awareness has on the discussion. If care staff can negotiate different discourses this may have a longer-term impact on how support is provided by staff and experienced by people with learning disabilities.

If this further research was successful, it could inform an intervention for clinical psychology to offer care providers, to support team reflection and curiosity about their own discourses and subsequent impact. Currently, local NHS services are not commissioned to provide direct sexuality work, which creates a gap in meeting the needs of people with learning disabilities. Proactive approaches which involve upskilling other professionals can help make a bigger difference to more people within this resource-limited framework. Giving care providers the tools to notice and understand the power of discourse could be a useful training strategy to increase reflection on issues of sexuality.

Strengths and Limitations

A strength of the study was user consultation in the focus group question design, as this ensured the group discussion reflected what people with learning disabilities deemed important. The user consultation group were asked for participation with data analysis to add credibility to interpretations, however all declined. Future participatory research would be beneficial; collaborating fully on the research questions, design and interpretations with those most affected by the research (Torre et al., 2015). This would help redistribute some of the power imbalances within research, empowering people with learning disabilities to be involved in research relevant to them. To ensure participatory research is viable adequate time and resources must be allocated to regular collaborative research meetings, with accessible materials and appropriate support. This was unfortunately not feasible within the scope of this study.

The sample size was decided upon due to the nature of the discussion and in-depth analysis requiring small group sizes. Sexuality is a sensitive topic; smaller groups are suggested to be advantageous for intense or complex topics (Morgan, 1995) and have been used successfully for sensitive studies (Bloor et al., 2001). The researcher must be aware of the dynamic nature of such groups and intervene to avoid participants becoming uncomfortable or distressed (Bloor et al., 2001). Given the potential for distress and virtual format of the focus groups, group sizes were limited at three-to-four participants to enable sensitive facilitation and response to group dynamics. Conducting three focus groups allowed in-depth analysis of qualitative data (Vasileiou et al., 2018) by enabling the researcher to fully immerse in the data, aiding good quality analysis.

The focus groups comprised of staff from within care teams which undoubtedly had pre-established dynamics. The Nuthatch and Skylark groups included team managers which likely affected the discourse due to the perceived power and authority held. The researcher facilitated and encouraged everyone to participate, but the data shows the less experienced staff spoke less whilst the team managers spoke more, setting the consensus of the talk. The study included staff with any amount of experience to try and recreate how these conversations may happen in typical workplace meetings. The dominance of the more experienced staff may reflect who speaks more in general staff meetings with managers typically taking the lead. This is not necessarily a limitation of the study (Smithson, 2000), but an interesting observation that was considered during analysis.

Researcher Reflexivity

Reflexivity was important during the research process to consider how the topic connected with me. As a sister of someone with a learning disability I have felt worried about safety when thinking of her sexuality, yet professionally connect to advocating for the sexual rights of people with learning disabilities. During analysis my interpretations may have been influenced by these previous experiences. I may have attended to this conflict in the data between safety and sexual rights as it reflected my own internal struggle. I presented extracts of the data at discourse analysis groups and within supervision to try and gain the perspectives of others in interpretation. However, I may have unconsciously chosen extracts that supported my preconceptions.

Conclusion

This study adds to the discursive literature exploring how care staff talk about sexuality for people with learning disabilities. Care staff constructed people with learning disabilities as sexually naïve or knowledgeable, and sex as unsafe, which justified the way they spoke about supporting people. Normalising sexuality discourses were much less commonly used. This has implications for potential training and reflective sessions clinical psychology could offer care staff to better support this area of people’s lives.

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Appendix A

Ethical Approval

CLES – Psychology
Psychology
College of Life and Environmental Sciences
University of Exeter
Washington Singer Building
Perry Road
Exeter
EX4 4QG
Web: www.exeter.ac.uk

CLES – Psychology Ethics Committee

Dear Victoria Booth

Ethics application - eCLESPsy002004
Can we talk about sex? A proposed qualitative study examining how care staff manage issues of sexuality for people with a learning disabil

Your project has been reviewed by the CLES – Psychology Ethics Committee and has received a Favourable opinion.

The Committee has made the following comments about your application:

- Please view your application at https://eethics.exeter.ac.uk/CLESPsy/ to see comments in full.
If you have received a Favourable with conditions, Provisional or unfavourable outcome you are required to re-submit for full review and/or confirm that committee comments have been addressed before you begin your research.

If you have any further queries, please contact your Ethics Officer.

Yours sincerely

Date: 11/03/2022

CLES – Psychology Ethics Committee
]

Appendix B

Participant Information Sheet

Title of Project: How do care staff construct the sexuality of people with a learning disability?

Researchers names:

- Vicky Booth, Trainee Clinical Psychologist, University of Exeter.
- Dr Cordet Smart, Research Lead for Doctorate in Clinical Psychology, University of Exeter.
- Dr Lorna Robbins, Consultant Clinical Psychologist, Somerset NHS Foundation Trust

You are being invited to take part in a research study. This study seeks to understand how sexuality is talked about for people with a learning disability. Please take time to consider the information carefully and to discuss it with family or friends if you wish, or to ask the researcher questions. Please remember that your participation is voluntary.

Purpose of the research:

Care staff have a significant role in supporting and enriching the lives of people with learning disabilities and are often relied on to provide practical and emotional support. Sexuality can be a sensitive and challenging topic to talk about. Research has shown that some care staff feel uncertain about how to support sexuality and find it a difficult subject to talk about. The way we talk about things can shape how we think and feel about them, therefore we want to explore how care staff talk about sexuality and support for people with a learning disability. It is hoped that this will enable us to better understand how care staff can help support sexuality for the people they work with.

Why have I been approached?

You have been approached because the care provider you work for has shown interest in participating. Several different care providers are being approached and it is hoped that a total of 4 staff teams will participate, with groups of approximately 4 staff.

What would taking part involve?

- If you agree to take part, you will be asked to attend an online focus group with other members of your care team. The focus group will last for approximately 40 minutes and there will be time at the end for us to reflect and discuss on the group process. The group will be facilitated by the researcher who will ask the team to talk about sexuality for people with a learning disability, and the support of this.

- The group will be videotaped as a way of recording what was said by the different group members. The discussion will then be transcribed into a word document, and everyone will be given a different name to ensure that what was said remains anonymous. The discussions from all the different care teams will then be analysed together for themes.

- A follow-up session will then be completed with your care team lasting up to 1 hour. During this the researcher will share the themes that emerged across all the care teams. This will also be anonymous. The session will enable the group to reflect on what was found and how this might relate to the support they provide.

What are the possible benefits of taking part?

We cannot guarantee that there will be any benefits to taking part in the study. However, the study may provide you with an opportunity to reflect on an important aspect of life for people with a learning disability. This may encourage the generation of new ideas or approaches to supporting sexuality for people with a learning disability. You will be able to contact the researcher individually to discuss sexuality for people with a learning disability in more detail. You and your care provider will be given an information pack with resources around sexuality for people with a learning disability, which may be helpful for the support you provide.

What are the possible disadvantages and risks of taking part?

There are no substantial risks associated with taking part in the study. The topic of discussion may potentially be sensitive and upsetting. If you were to find the conversation distressing, you can leave the group at any time and speak to the researcher individually for support. The groups will be completed with your staff team, which potentially may feel uncomfortable as you will be discussing sexuality for the people you support in front of your colleagues. The researcher will reassure the group that the discussions should be open, reflective and remain confidential within the group.

What will happen if I don't want to carry on with the study?

You can stop taking part in the study at any time without having to give a reason by contacting the primary researcher Vicky Booth (vb327@exeter.ac.uk) who will destroy your personal data. If you decide to withdraw **after** the focus group, your contribution to the video recording cannot be destroyed. However, your individual statements can be removed from the transcript, and any quotes will not be included in the final report. You can also withdraw from the follow-up session by contacting the researcher and stating that you do not wish to attend the follow-up group.

How will my information be kept confidential?

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

The focus groups will be videotaped and then the conversation will be transcribed into a written format. These will be password protected and stored on a secure computer. The video recordings will be kept for up to 1.5 years to ensure data has been accurately transcribed. The written transcriptions will be anonymised using pseudonyms and kept for up to 5 years, on a secure computer. After such time the data will be destroyed. Personal data will only be held by the research team and will **not** be shared with others, including people within your organisation or workplace.

You can choose to opt for your contact details to be kept and be informed about the follow-up session and the outcomes of the project. These contact details will be kept securely, and passport protected. Personal contact details will be destroyed after 2 years.

Is there an exception where you would breach confidentiality?

The only exception to keeping information confidential would be if the focus group conversation indicated that an individual was at risk, for example due to safeguarding concerns or inappropriate practice. If this situation arose then safeguarding procedures would need to be followed which might involve breaching confidentiality.

What will happen to the results of this study?

An optional follow-up session will be completed to share the results of the study with the people who participated. A summary of the findings may also be shared with your organisation. You will not be personally identifiable in any write-up or presentation of the study results. Anonymised quotes may be used with a pseudonym so that these are not identifiable.

It is intended that the thesis project will be summarised into an article for publication in an academic journal. A Service User Consultation Group will also be provided with an accessible summary of the project. There may be opportunities for the study to be discussed at a conference.

Who is organising and funding this study?

The project is being completed as part of the primary researcher's training for the Doctorate in Clinical Psychology programme at Exeter University.

Who has reviewed this study?

This project has been reviewed by the Research Ethics Committee at the University of Exeter (Reference Number: eCLESPsy002004).

Further information and contact details

You can contact the research team for further information about the study and/or to take part.

- The primary researcher is Vicky Booth (vb327@exeter.ac.uk).
- The primary research supervisor is Dr Cordet Smart (C.A.Smart2@Exeter.ac.uk).
- The secondary research supervisor is Dr Lorna Robbins (Lorna.Robbins@sompar.nhs.uk).
- If you are dissatisfied with any aspect of the project and wish to complain please contact Gail Seymour (Research Ethics and Governance Manager) at g.m.seymour@exeter.ac.uk or on 01392 726621.

Thank you for your interest in this project.

Appendix C

Consent Form

Participant Identification Number:

CONSENT FORM

Title of Project: How do care staff construct the sexuality of people with a learning disability?

Name of Researchers: Vicky Booth, Trainee Clinical Psychologist, University of Exeter.

Dr Cordet Smart, Research Lead for Doctorate in Clinical Psychology, University of Exeter.

Dr Lorna Robbins, Consultant Clinical Psychologist, Somerset NHS Foundation Trust

Please

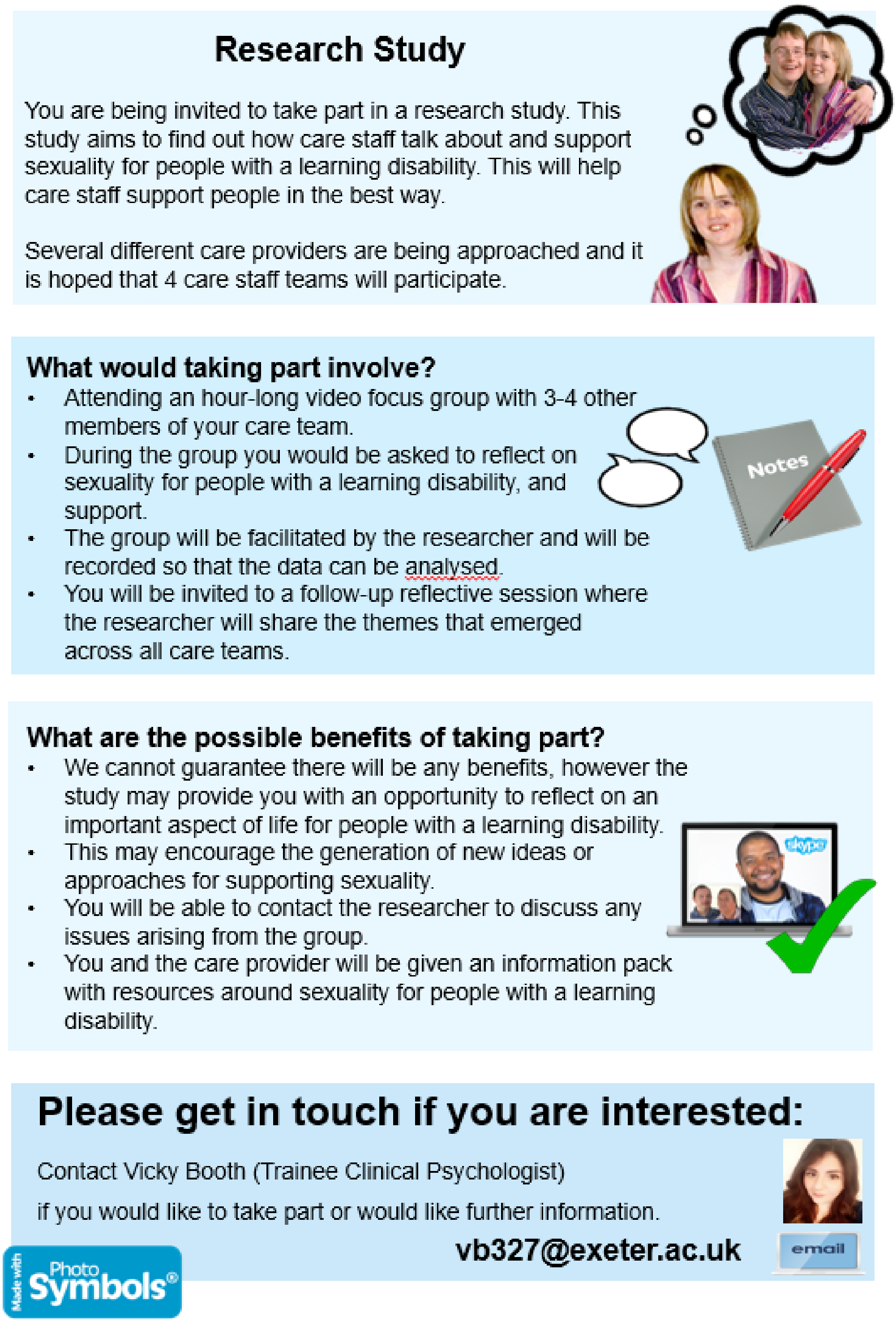
1. I confirm that I have read the participant information sheet dated 29th March 2021 for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected. ☐
3. I understand that relevant sections of the data collected during the study may be looked at by members of the research team, individuals from the University of Exeter and the Service User Consultation Group where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that taking part involves anonymised interview scripts where quotes could be included in an academic publication. ☐
5. I understand that taking part involved anonymised interview scripts to be used for inclusion in an archive for up to 5 years. ☐
6. I understand that taking part involves identifiable video recordings to be used for the purposes of inclusion in an archive for a period of up to 3 years. ☐
7. I agree that my contact details can be kept securely and used by researchers from the research team to contact me about the follow-up session and outcome of the study. ☐
8. I agree to take part in the above project. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of researcher taking consent	Date	Signature

When completed: 1 copy for participant; 1 copy for researcher/project file

Appendix D

Recruitment Information



Research Study

You are being invited to take part in a research study. This study aims to find out how care staff talk about and support sexuality for people with a learning disability. This will help care staff support people in the best way.

Several different care providers are being approached and it is hoped that 4 care staff teams will participate.

What would taking part involve?

- Attending an hour-long video focus group with 3-4 other members of your care team.
- During the group you would be asked to reflect on sexuality for people with a learning disability, and support.
- The group will be facilitated by the researcher and will be recorded so that the data can be analysed.
- You will be invited to a follow-up reflective session where the researcher will share the themes that emerged across all care teams.

What are the possible benefits of taking part?

- We cannot guarantee there will be any benefits, however the study may provide you with an opportunity to reflect on an important aspect of life for people with a learning disability.
- This may encourage the generation of new ideas or approaches for supporting sexuality.
- You will be able to contact the researcher to discuss any issues arising from the group.
- You and the care provider will be given an information pack with resources around sexuality for people with a learning disability.

Please get in touch if you are interested:

Contact Vicky Booth (Trainee Clinical Psychologist)

if you would like to take part or would like further information.

vb327@exeter.ac.uk

Appendix E

Consultation Advert

My name is Vicky Booth.

I am learning to be a psychologist at Exeter University.

I am doing some research

I want to find out how care staff help people with sex and relationships. This will help care staff support people in the best way.

How will I find this out?

I will talk to care staff about helping people with sex and relationships. I want to make sure I ask care staff the right questions. I want to know what you want to know about sex and relationships.

What will happen if we talk?

We can talk using a video call on a phone or laptop. We can talk about:

- Who care staff are.
- What you think care staff can do that is helpful and unhelpful.
- What is important about sex and relationships.

If we talk
We don't have to talk about anything you don't want to.
You can have a break or stop when you want.
You can have someone with you or talk to me alone.

What you tell me
I will write down what we talk about.
This will help me think of questions to ask care staff.

What you say will be private
This means I won't tell anyone your name or what you said.

I will need to tell somebody if I am worried someone might get hurt.

Get in touch

07935752346

vb327@exeter.ac.uk

Appendix F

Consultation Interview Schedule

Thank you for talking with me today.

The reason we're talking is because I would like your help. I am doing some research with care staff and I want to make sure I ask the right questions. You were interested in helping me/X thought you might be a good person to help me think about this.

Today we can talk about:

- Who care staff are
- What care staff can do that is helpful and unhelpful
- What is important about sex and relationships

Remember:

- We can stop or take a break whenever you want, say I want to stop or take a break.
- You don't have to talk about anything you don't want to. If I ask a question you don't want to answer, say I don't want to talk about that and we can talk about something else.
- If I ask a question and you don't know the answer just say I don't know. There are no right or wrong answers, I just want to find out what you think.

Shall we get started or do you want to tell me a bit about yourself first? (Intro activity?)

Care Staff

- When we say care staff, what kinds of people does this make you think of?
- *Give examples if unsure, I am looking for staff who help a person where they live…*
- Have you had any care staff?
- Has anyone you know worked with care staff?
- What kinds of things do they help people with

Support

I want to help care staff support people in the right way to live their best life. So I am interested in what support is good, or helpful, and what support is bad or unhelpful.

Based on examples if possible, otherwise more general about being helped

- Have you been helped with XYZ – what was good or bad about this?
- What can they do which is helpful?
- Can you think of a time someone did something that was helpful?
- For unhelpful – what could they have done differently that might have been better?

Sex and Relationships

- When we say sex and relationships, what does this mean to you?
- What is important about this?
- Do people sometimes need help to do this?
- Do you know anyone who may have needed help with this…what was good about the support/could have been better?

Appendix G

Focus Group Interview Schedule

Thank you all for agreeing to take part. We have about 45 minutes to talk about sexuality for people with learning disabilities, and how this subject overlaps with support. I am going to record the conversation and will stop after 45 minutes, and we will then debrief. It is OK for everyone to share different ideas and alternative views – that is the purpose of the group. Please keep any views expressed during the focus group confidential between the group members. I have some questions to generate discussion and am going to invite you to have a conversation about these questions between yourselves:

1. How does everyone feel coming to the group today to talk about sexuality for people with a learning disability?
    - What does this make you think about?
    - How did people feel before coming to this meeting today?
    - Any worries or hopes for the conversation?
2. Can you tell me if, and how, this topic comes up within your role?
    - What discussions have you had with other staff about this?
    - How important is this topic within your role?
3. What discussions have you had, or what support have you given, around sex and relationships?
    - Has anyone discussed this with a service user?
    - Has anyone ever supported anyone with sex and relationships?
    - Has a service user ever asked questions about sex and relationships?
    - What did it feel like as a staff member?
    - How do you think the service user responded to this?
    - Were there any other views (e.g. family, other professionals), and how were they involved? Looking back what are your reflections on this?
    - Have you ever introduced the topic with a service user?
    - What kind of support might people need?
        - From talking with people with learning disabilities they spoke about opportunities to meet others, moral support, social skills, having questions answered, are these issues similar or different to those you would think about?

4. What comes to mind when thinking about responsibility – whose responsibility is it to raise as a topic for discussion?
    - What considerations are there when thinking about whose responsibility it is to support sex and relationships?
    - Is it the service users' role to bring the subject up, or should staff actively ask and support? What might be the pros and cons of each position?
    - How comfortable and confident would you feel bringing the subject up?
    - How comfortable and confident do you think service users would feel bringing the subject up?
    - What are people's thoughts about sex and relationships in relation to your job role?
    - What support might staff want around the subject?

Debrief

Thank you so much for your rich conversation. We value people contributing to a sensitive discussion and recognise that everyone has different experiences, and the conversation may have different meanings for different people. This may have been uncomfortable or difficult and I ask that everyone is accepting of everyone who has contributed.

We have some time now just to debrief but I also encourage anyone to contact me individually if you want to talk about how this has felt or any issues that it may have brought up. I will also offer a follow-up reflective session once the research has been completed where I can share the themes that were generated from the focus group and we will have the opportunity to reflect and discuss them.

- How is everyone feeling?
- Is there anything that people are going to take away?
- Is there any self-care you will do?
- How similar or different is this to conversations you might have at work?

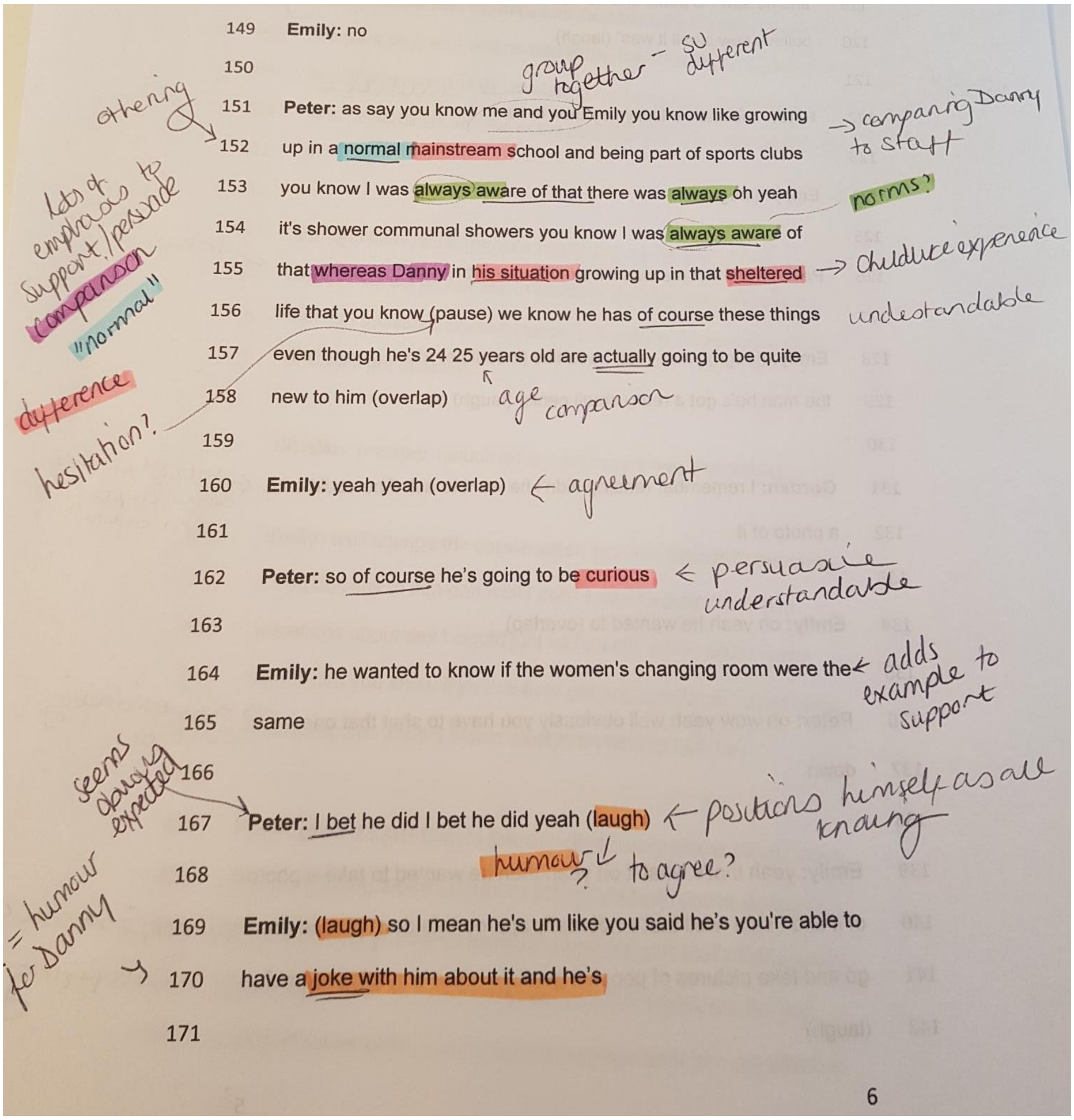
Although specific views need to be kept confidential if this conversation has prompted you to reflect on any support that is provided, please do discuss this with your manager or colleagues.

I can also give a brief summary of the purpose of the research: The research is exploring how we talk about sexuality and supporting sexuality for people with a learning disability. The way we talk about sexuality, the words and expressions we use, can make a story about sexuality and learning disability, that can then impact their real world experiences. For example, people might just not talk about sexuality for people with learning disabilities, and the story this might suggest people with learning disabilities do not have sexuality. Whereas we know people with learning disabilities do have sexuality and that this is important for their wellbeing. But in society this might be considered quite a difficult topic to discuss. I am interested in how care staff talk about sexuality, because of the real opportunities and positive impact that you can have on people’s lives.

If any concerns: When we spoke about that it made me a bit uncomfortable, and it just made me think we might need to discuss with the manager to think about doing something to support differently.

Appendix H

Extract of Data Analysis



Emily: no

Peter: as say you know me and you Emily you know like growing up in a normal mainstream school and being part of sports clubs you know I was always aware of that there was always oh yeah it's shower communal showers you know I was always aware of that whereas Danny in his situation growing up in that sheltered life that you know (pause) we know he has of course these things even though he's 24 25 years old are actually going to be quite new to him (overlap)

Emily: yeah yeah (overlap)

Peter: so of course he's going to be curious

Emily: he wanted to know if the women's changing room were the same

Peter: I bet he did I bet he did yeah (laugh)

Emily: (laugh) so I mean he's um like you said he's you're able to have a joke with him about it and he's

6

othering

lots of emphasis to support/persuade

comparison

"normal"

difference

hesitation?

group together – so different

→ comparing Danny to staff

norms?

→ childhood experience

understandable

age comparison

← agreement

← persuasive understandable

← adds example to support

seems [illegible] expected

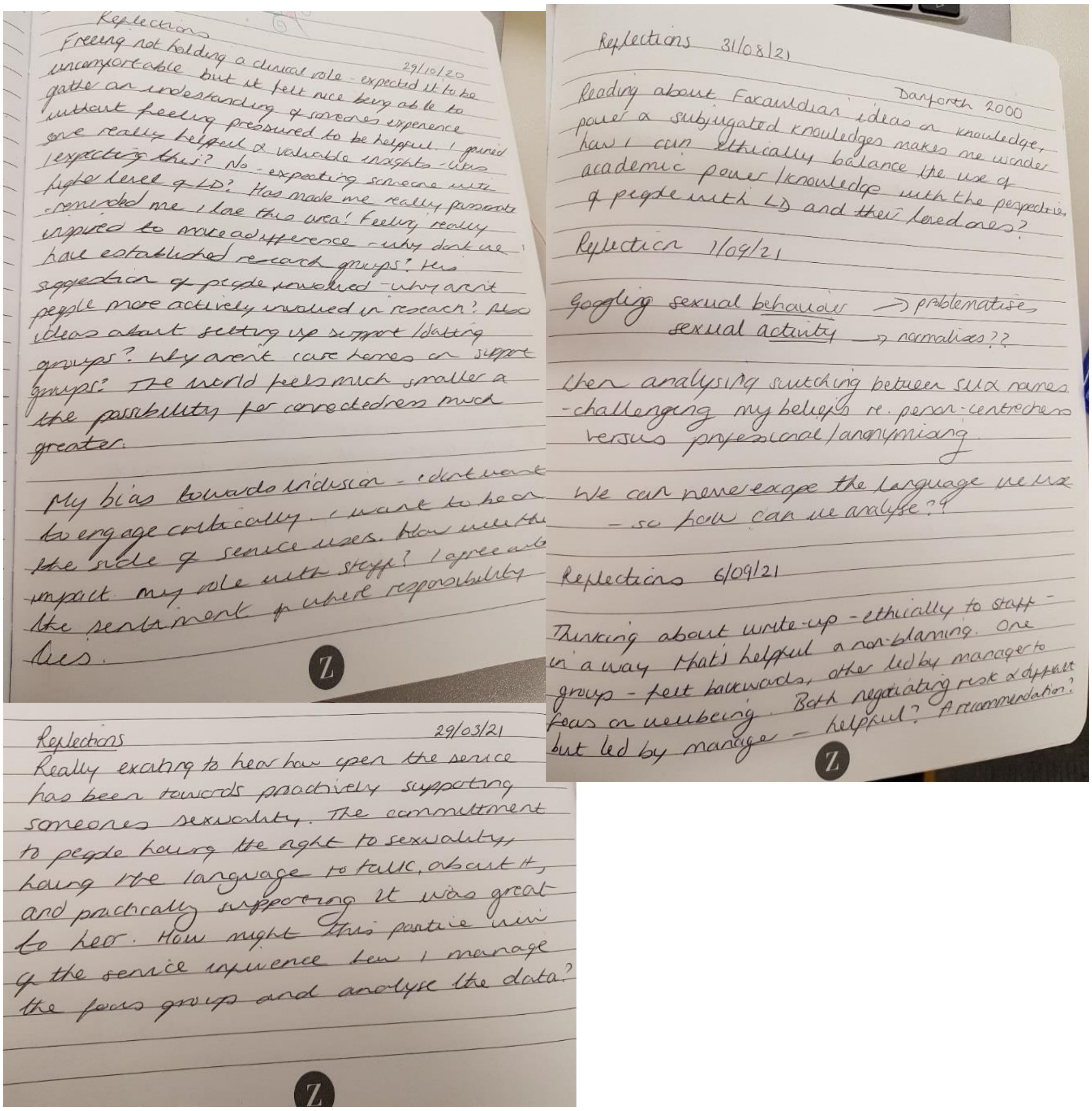
← positions himself as all knowing

humour? to agree?

= humour for Danny

Appendix I

Reflective Log Excerpts



Reflections
29/10/20
Freeing not holding a clinical role - expected it to be
uncomfortable but it felt nice being able to
gather an understanding of someones experience
without feeling pressured to be helpful. I gained
one really helpful & valuable insights - was
I expecting this? No - expecting someone with
higher level of LD? Has made me really passionate
- reminded me I love this area! Feeling really
inspired to make a difference - why don't we
have established research groups? His
suggestion of people involved - why aren't
people more actively involved in research? Also
ideas about setting up support / dating
groups? Why aren't care homes on support
groups? The world feels much smaller &
the possibility for connectedness much
greater.

My bias towards inclusion - I don't want
to engage critically. I want to hear
the side of service users. How will this
impact my role with staff? I agree with
the sentiment of where responsibility
lies.

Reflections 29/03/21
Really exciting to hear how open the service
has been towards proactively supporting
someones sexuality. The commitment
to people having the right to sexuality,
having the language to talk about it,
and practically supporting it was great
to hear. How might this positive view
of the service influence how I manage
the focus groups and analyse the data?

Reflections 31/08/21

Reading about Foucauldian ideas on knowledge, Danforth 2000
power & subjugated knowledges makes me wonder
how I can ethically balance the use of
academic power / knowledge with the perspectives
of people with LD and their loved ones?

Reflection 1/09/21

Googling sexual behaviour → problematises
sexual activity → normalises??

When analysing switching between SU & names
- challenging my beliefs re. person-centredness
versus professional / anonymising.

We can never escape the language we use
- so how can we analyse??

Reflections 6/09/21

Thinking about write-up - ethically to staff -
in a way that's helpful & non-blaming. One
group - felt backwards, other led by manager to
focus on wellbeing. Both negotiating risk & different
but led by manager - helpful? A recommendation?

Appendix J

Dissemination Statement

The dissemination of this research study is intended to reach people with learning disabilities, care staff, clinicians and academics. The care providers and participants who participated in the study will be given the opportunity to discuss the research findings and can receive a copy of the results of the study. The user consultation group will be given the option of receiving an accessible summary and discussing the findings. The research will also be submitted to a peer-reviewed journal, the British Journal of Learning Disabilities, with the hops that it will be published.

Appendix K

Copy of Journal Instructions for Authors

Link to British Journal of Learning Disabilities Author Guidelines:

https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.html

Appendix L

Copy of Confidentiality Agreement

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I agree that I will not use for myself or disclose to others any confidential information or other proprietary data I may have gained as a result of working for Devon Transcription. I agree that I will not solicit any client of Devon Transcription either directly or indirectly, for my benefit or the benefit of a third party.

I understand that I may be held responsible for any damages suffered by Devon Transcription which result from negligence on my part in this regard.

Signed: ____

Name (printed): ____

Date: ____

Signed on behalf of Devon Transcription: ________________________________