



# The University of Bradford Institutional Repository

<http://bradscholars.brad.ac.uk>

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher's website. Access to the published online version may require a subscription.

**Link to publisher's version:** <https://doi.org/10.1177/1363460715620572>

**Citation:** Rogers C and Tuckwell S (2016) Co-constructed caring research and intellectual disability: an exploration of friendship and intimacy in being human. *Sexualities*. 19(5-6): 623-640.

**Copyright statement:** The final, definitive version of this paper has been published in *Sexualities*, vol 19/issue 5-6 by SAGE Publications Ltd, All rights reserved. © 2016 The Authors.

### **Author biographies**

Chrissie is a Senior Lecturer in Sociology at Aston University. She has just completed her second monograph called *Intellectual Disability and Being Human: A care ethics model* and prior to that she edited with Susie Weller, *Critical Approaches to Care*. Chrissie has worked at Anglia Ruskin, Brunel and Keele universities, and before that she held an ESRC post-doctoral fellowship at the University of Cambridge. Her ESRC PhD was from the University of Essex where she researched families of children identified with ‘special educational needs’ in the Sociology department. Chrissie published her PhD research in a range of journals and as a monograph called *Parenting and Inclusive Education*.

Sherrie participates in Crafty Drama (with Essex Cares) and works part time for Jacques Vert. She has a long term boyfriend and very much likes to be involved in all things creative.

### **Abstract**

For this paper, *emotional* and *socio-political* questions lie at the heart of relationships in understanding intellectual disability and what it is to be a human. While the sexual and intimate is more often than not based on a private and personal relationship with the self and (an)other, the sexual and intimate life of intellectually disabled people is more often a ‘public’ affair governed by parents and/or carers, destabilizing what we might consider ethical and caring practices. In the socio-political sphere, as an all-encompassing ‘care space’, social intolerance and aversion to difficult differences are played out, impacting upon the intimate lives of intellectually disabled people. As co-researchers (one intellectually disabled and one ‘non-disabled’) we discuss narratives from a small scale research project and our personal reflections. In sociological research and more specifically within disability research it is clear we need to keep sex and intimacy on the agenda, yet also find ways of doing research in a meaningful, caring and co-constructed way.

# Co-constructed caring research and intellectual disability: An exploration of friendship and intimacy in being human

## Introduction

Despite work in the area of sexuality, sexual health and reproduction, (Hollomotz 2011, Johnson and Walmsley with Wolfe 2010) cultural assumptions about intellectually disabled people and their intimate and sexual life are so embedded, relationship performances that fall outside social norms, are at best stigmatising (Goffman, 1963 Graham, 2010, Shildrick 2009). Prejudice is so ingrained within the emotional sphere, deeply embedded psycho-social reactions to behaviours outside social norms are evident (Barnes and Mercer 2003, Goffman, 1990). Namely, people who have limited intellectual capacity are *not supposed* to enjoy intimacy and all the pleasures and challenges that come with it. Moreover intellectually disabled people have been deprived of their sexual rights and according to the 'United Nations Convention on the Rights of Person with Disabilities (United Nations, 2006) and agreements of other legislative bodies, they possess these rights, but in practice these rights are systematically denied' (Richards *et al.* 2012: 103). Critically, 'little progress regarding the sexual rights for peopled with intellectual disabilities has been achieved' (*ibid*).

Anonymous others make decisions about the private, intimate, sexual life of those who are unable to have what they want from life, which is more often than not, family relations, a lover and friends (Hollomotz 2011, Johnson and Walmsley with Wolfe 2010, Richards *et al.* 2012, Rogers, 2009). This has a dramatic negative impact upon intimate and sexual identity. On the basis of this, and with a genuine desire to co-construct a paper with someone who has an insight into this area of life, (Sherrie, my adult intellectually disabled daughter) we attempt to build a narrative, in a careful and caring manner. Hence, this paper is about doing research with another person who has an intellectual impairment, and in this case who can communicate verbally, but is less able to read and write. It is also about reflecting upon and exploring themes from empirical and theoretical research, as well as personal narratives, on sexuality, friendship and leisure time within a care ethics model of disability (Rogers, in press).

*A care ethics model of disability: framing a co-constructed research process*

Trying to carry out social research and understand social justice, ethics and morality from an 'objective' or homogenous standpoint is simply not helpful. Therefore, in recent years I have been working on developing a care ethics model of disability that currently, theoretically, responds to and works with intellectually disabled people. The social model was a ground breaking way of understanding the differences between disability and impairment, and paved the way for change. Largely because prior to the social model, the medical model placed emphasis on impairment and as a consequence pathologised disabled people. Disability was considered *within*, and the person with impairment in need of repair. As such, disability according to Oliver (1996: 22) was deemed 'a form of disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments'. Therefore barriers to social and physical inclusion were in place to subjugate those regarded as less than human (Rogers, in press). The purposes for this paper, in working with an intellectually disabled woman in co-constructing research is to explore caring and careful research processes in the context of friendships, intimacy and sexuality, so that researchers and practitioners alike can begin to map, understand and take forward caring and careful work, not only for intellectually disabled people but for *all people*.

There are three spheres of caring work, but these are currently populated with many careless spaces: the *emotional caring sphere*, where love and care are psycho-socially questioned, the *practical caring sphere*, where day-to-day care is carried out relationally, and the *socio-political caring sphere*, where social intolerance and aversion to difficult differences are played out. These three spheres interact in complex ways. They are the foundation of a care ethics model of disability and grounded in social and political relations that seek caring legal and cultural processes. Many social researchers work with human participants, and to carry out careless research is systemically abusive. However, often research is maligned if there are too many emotions involved, yet this very research, with people, is impossible to do well with complete objectivity, or without caring. Within a feminist ethics of care, humans are relational. In addition to this all humans are vulnerable and therefore all can be both care givers and receivers. This includes researchers and participants.

For Tronto (and others such as Herring, 2013: 57) *trust* is key, for an ethics of care, and given that care is often both ‘physical and psychic intimacy, good care grows out of trust that develops among those giving and receiving care’ (Tronto, 2011: 162-163). Trust is also key in good research relationships. Yet trusting research relationships, particularly with those who have an intellectual impairment does not easily fall into place. Tronto goes on to say that care ‘creates a *relationship* among the parties caring and being cared for’ and critically this ‘relationship is not a “thing”’ (Tronto, 2011: 163, emphasis in original). All researchers via a care ethics model of disability, ought to commit to hearing what less powerful others have to say. Yet it is apparent that people do not listen, or hear. At the very least those identified as ‘marked’ are seen to exist at the bottom of the human hierarchy. Tronto (2011), in her work is talking about women of colour in the USA, but with respect to intellectually disabled people and their caring relations, they too are marked. It is because intellectually disabled people are marked that a care ethics model is essential in framing research processes.

Within a care ethics model, via all three proposed caring spheres, for co-constructed research human safety, trust and caring are key. Notably, Robinson (2011) interrogates human security by using a feminist approach to an ethics of care and it is here I begin to see how the emotional, practical and socio-political spheres leak into and out of private and public life of humans (more often than not women) in complex ways. Moreover, all humans are in danger of violence and abuse, systemic or otherwise; sex, intimacy and care are no longer private issues. The public domain, or the socio-political sphere, has to take into account all human beings. Besides, it is evident that philosophically, moral reasoning based on justice which ‘asserts that morality is about the objective application of universalizable principles among mutually disinterested, disembodied individuals’ (Robinson, 2011: 5) is wholly unacceptable. We do not live in a world of abstraction; we live in a world of relationships, *in the real world*.

It is within the day-today life that Sherrie and I want to explore intimacy, sexuality and friendships for intellectually disabled people, and it is the emotional and moreover, psycho-social that lie at the heart of relations, the self and a care ethics model. In this context, we ask, are caring and careful relations always about reciprocity, friendships and intimacy and how are they managed when evidently what we often consider as private feelings and actions are

made public and are then interpreted by others? Intimacy and relationships for intellectually disabled people have been storied in a way that is beyond caring and friendship and is indeed care-less. Often described as unable, unwilling, too willing, uncaring, not worthy; intellectually disabled people have been left without care, lonely and dehumanised. We would like to identify how intimate relationships and friendships benefit the everyday and how they can positively promote carefulness across all three caring spheres within and a care ethics model of disability, and in this process demonstrate caring and careful research practices.

As it is, Sherrie was part of an initial scoping meeting and focus group for a small scale research project called ‘Stories of relationships and intimacy with young intellectually disabled people and their parents: an exploration of intimacy and friendship’, but after discussion wanted to be a part of the analysis process. Subsequently we carried out further research meetings as co-researchers. The short section below discusses literature and research around friendships and sexuality. We go on to talk in some detail about methods. The final two sections explore in friendships and intimacy as a foundation to life, loss, expectations and dreams. Concluding remarks finish the paper as we ponder the challenges and rewards of co-constructing research. Social interaction, emotional connection and intimacy are all part and parcel of being human – it is unethical and unjust to deny anyone such relations.

### *Sexuality, friendships and being human – an introduction*

For the purposes of this paper the emotional and socio-political lie at the heart of relationships in understanding what it is to be a human. Emotional, because the sexual and intimate is often understood as a private and personal relationship with the self and (an)other in understanding being human (Groner 2012, Lafferty *et al.* 2013). Yet also socio-political as for intellectually disabled adults, sexual and intimate experiences are often a public affair governed by parents and/or carers (Foley 2012, Hollomotz 2011, Shakespeare 2006), destabilizing what we might consider a human right to make decisions about our body and life (for example about contraception see McCarthy, 2009, 2010). Not being recognised as a potential sexual partner, or experiencing lack of autonomy due to a physical disability (Sakellariou 2012, Siebers 2012), being socially and emotionally isolated as a result of

mental illness (Gillespie-Sells *et al.* 1998, Shakespeare, 2006) and feeling unloved, lonely and infantilised, as well as experiencing, at times, extreme governance and violence - because of an intellectual impairment (Hollomotz 2011, Kelly *et al.* 2009, Kim, 2011, Richards *et al.* 2012) are disabling processes and dehumanizing.

It is well established how significant intimacy and friendship relations are in human interaction and writers across disciplines talk about the need, desire, and want of friendships and intimacy (Pahl 2000, Spencer and Pahl 2006). It is important therefore to understand the dehumanizing impact of restrictions on friendships and intimacy for particular groups of people, especially at a time when family structure, social and geographical mobility, social networking and ways of meeting people are changing and as 'traditional forms of social glue decline or are modified' (Pahl, 2000: 12). In this context different ways of reconstituting personal networks and 'family' based on *choice* rather than heritage (Gabb 2008) are apparent. This 'choice' of personal ties for many intellectually disabled people is fractured or even absent (Walmsley *et al.* 2013, Hollomotz 2011). Yet human beings throughout a life course, generally rely on those who care 'for', 'with' and 'about' them and ultimately would prefer to feel secure in the choices made about close connections, intimate relations and family ties. But 'the dominant ontology of autonomy – of isolated, self-reliant moral selves – does not adequately reflect peoples lived experience in most communities around the world' (Robinson 2011: 29). Moreover, for intellectually disabled people, lack of 'choice' or even lack of resources to access certain social networks is problematic.

Indeed, the management of personal relations for many, might go unnoticed, but for intellectually disabled people this can become part of the care work (professional sphere) and emotion work (mothering, friendships, family other) narrative (Hollomotz 2011; Rogers, in press, 2013; Shakespeare 2006). Third parties become involved in what is considered a private matter and the loss of agency is evident as caring involves practical and emotional labour. In many ways this intrusion into the personal is the antithesis of what intimate relationships are about emotionally, though necessary in some cases. However, the blurred boundaries in caring 'for', 'about' and 'with' (Philip *et al.* 2013, Noddings 1995, Rogers, 2013) intellectually disabled people and intimate relations confuse sexuality and relationships status (Rogers, 2009).

### **Methodological beginnings and co-constructing**

### *Introduction – co-construction*

Sherrie is an intellectually disabled adult woman. She attended as a participatory research member, one scoping meeting and one focus group for a small scale project called ‘Stories of relationships and intimacy with young intellectually disabled people and their parents: an exploration of intimacy and friendship’. After the research had been completed, and in a discussion with Sherrie, she told me she wanted to be a part of the analysis and interpretation process. Subsequently we carried out numerous research meetings to develop and then discuss the themes emerging from the data. Throughout this process, caring and carefulness were always a prime concern, but despite caring practices, there can often be misunderstandings, miscommunications and as such reflection on the research process is critical, but not doing research with intellectually disabled people about their lives is unethical and careless.

It would be derisory to say that carrying out research with people who are intellectually disabled is easy. In his research with intellectually disabled adults, McClimens (2007: 272-273) ended up temporarily parting company with colleagues when tensions arose around such things as ‘false starts, missed deadlines and generally shared failure to produce even a few lines of genuinely shared writing’. Indeed, he went on to say that ‘the language used to describe the collaborative research process was clearly divisive and could become the site of a struggle for control, for knowledge and for truth’ (*ibid*: 273). Manning (2009: 162) also found challenges with the ethical process and implementation, due to the prescriptive nature of third party consent, which ‘actually served to undermine the advocacy rights of people with learning disabilities who were more capable of making informed decisions’ (*c.f.* Boxall and Ralph 2010). Yet do we ignore ways of doing research that do not always feel comfortable? How ethical can we claim to be when not all our research participants and/or co-researchers are non-disabled (Boxall and Ralph 2010, Walmsley 2004)? Moreover, do we exclude secrets and silences that emerge from a research process that might expose us as careless or flawed researchers, so as to claim academic legitimacy? (Cooper and Rogers 2015, McClimens 2007, Ryan-Flood and Gill, 2010). As with feminist claims to understand women’s position as an ‘insider’, we consider the findings of our research with a duality of insider/outsider status and with reflexivity (Ribbens and Edwards 1998).

Notably it is no longer ethical to consider intellectually disabled people as subjects simply to be surveyed (Boxall and Ralph 2009, Johnson 2009, Nind and Vinha 2012). If an

intellectually disabled person can contribute through critical conversation, it would be unethical and careless to exclude her. In this case, Sherrie discussed in detail her desire to participate, without support, and significantly, Manning (2009) found that those who did not have profound and multiple disabilities were hindered by an advocate. They wanted to be involved in their own right and consent for themselves. Sherrie did not want a third party negotiator to position herself as a researcher. When we come to question the mother/daughter relationship as researchers, we know that families and more often mothers have an important and necessary part to play in disability research (Rogers, 2007, 2013, Foley 2012, Hillyer 1993, Runswick-Cole and Goodley 2013, Ryan and Runswick-Cole 2008, Walmsley and Mannan 2009). Moreover, we are not alone in doing research together as family members. Adler and Adler (1997) included their children in the research (not without tensions), and Booth and Booth (1998) and Duncombe and Marsden (1993) also wrote together as partners. Co-constructing research with a close family member is not new in sociological research and can be part of an inclusive research tradition (Walmsley, 2004), and within a care ethics model framework. Sherrie fully participated in interpreting and discussing the data. As an example of this careful process we write a sub-section below to exemplify the co-constructed nature of discussion.

#### *What is research?*

When writing this research paper Sherrie and I started by having a discussion about what research entailed. This is what followed.

*'What is research, I ask Sherrie'? 'It's when we get ideas'. 'Yes', I reply, 'and what do we do with these ideas'? I continue. 'Well we put them on paper, then we go to the computer, and we save them'. .... 'What about after that'? I probed. 'Once we have put it all together, we then publish it, put it in the shops so other people can look at it. We show other people. But we don't tell people about the names in the research, not real names'... We carried on talking about who might be interested in our research and why we might do it. Sherrie told me 'we do it to help people, like other people and our friends and family or we might tell our local MP'.*

I went on to ask her if she understood what co-constructed means.

*'No I don't know what that means' she replied. 'That's not a problem, it's not a word we use all that often really' I respond. I went on to talk about how we might build a piece of furniture together, or cook together. 'Oh, I get it'. We do it together. We do the research together'. 'Yes exactly'. 'But I can't read or write those things'. She*

*looked at me, and I said. 'No worries, I can do that, and we can talk about the narratives from the small scale research – the focus group and interviews and see what they say to you as well as to me'.*

It is at this point we would again like to share an example of how knowing someone really well can aid a caring and careful research process rather than hinder it, largely because it contextualises a reality, rather than leaving it to an unknown other to interpret (*c.f.* Walmsley and Mannan 2009).

Sherrie and I came to our first research meeting and I had no input into the notes that she made apart from the verbal discussion that took place. I did not ask her to bring a note book, but she did nevertheless. The excerpts she wanted to highlight are based on what we discussed about research seen above. (In brackets some interpretation of mine are added).

*I want to use my name, codewith togeve, (constructing together) with geve and start pot it geve pot a book toger. What rase when we get eye dear we pot on bit papea (we put ideas on paper) then we pot on copon (we co participate) then we pot the book toger (the paper together) [...] then you can pop in shop so over (other) pople can get and show over pople family friend work cole (colleagues) then we help them by ask ok [...] we mite go to lock pole (we might ask people if our research is good and see a local politician).*

Without the verbal discussion and the intimate and knowing context it would be very difficult to understand this narrative, but the activity of making notes and discussion is critical in the caring research process. Importantly '[i]t is difficult and risky for 'outsider' researchers to second-guess the motivations and interpretations of individuals who may view the world very differently' (MacLeod *et al.* 2013: 1).

#### *Stories of relationships and intimacy - a small scale research process*

A qualitative research project that was funded by the Childhood and Youth Research Institute at Anglia Ruskin University informs part of this paper. The project came about as a result of previous research (Rogers, 2009, 2010) and a recognition that, 'little progress regarding the sexual rights for people with intellectual disabilities has been achieved' (Richards *et al.* 2012: 103). The project was carried out over a period of three months in 2011 and explored young intellectually disabled people's narratives (Taylor Gomez 2012, Kelly *et al.* 2009, McCarthy 2010). The research aimed to explore whether intellectually disabled young people were given the opportunities to practice their rights to privacy, marriage, childrearing, retaining

fertility, everyday friendships and leisure time. In addition narratives from parents and carers were sought (Runswick-Cole and Goodley 2013, Walmsley and Mannan 2009). The aims were to map how young intellectually disabled people make sense of their intimate, emotional and relationship experiences; to explore how parents (or carers) understand and engage with their intellectually disabled 'child's' sexual identities and relationships; and to map and record how to do research inclusively.

By obtaining stories from young intellectually disabled people as well as parents/carers via an initial scoping meeting, a focus group interview and two in-depth qualitative interviews we wanted to chart intimacy, sexuality, 'care' and exclusion in their lives. Furthermore, as part of the study objectives we initiated a research process that included young disabled people as co-researchers in an attempt to carry out participatory, caring or inclusive research (Lundy *et al.* 2011, MacLeaod *et al.* 2013, Walmsley and Johnson 2003). Participants were involved at all stages and they were encouraged to reflect upon how we carried out the research and advise us about any changes that we ought to make. The study began with an exploratory scoping meeting. Key people involved were: two parents, two intellectually disabled young people, a representative from Mencap, a youth worker and an education professional and two researchers. In this meeting we discussed what everyone thought the main issues were in order to ascertain what issues were the most important to follow up in the proposed interviews. This was followed by a focus group with 5 intellectually disabled young people aged between 23 and 30. They were recruited from a regional leisure group for young intellectually disabled people where we visited and explained our research and subsequently invited people to join the research project. After this we carried out two in-depth interviews with Ben, a gay intellectually disabled man and Teela, a heterosexual intellectually disabled woman, both in their 20s. Both Ben and Teela were at the scoping meeting and focus group and were happy to have one to one interviews.

We gained ethical clearance from our university research ethics panel. We also found it really useful to think about these questions throughout the process.

- Whose voice is narrated throughout the research?
  - The young person or the researcher?
- Who consents to the research?
  - The young person or the gatekeeper?

- How *included* in the *whole* research process (from design to analysis) is the young person?
- What role does the researcher play in the life of the young person and how does that relationship develop?
  - Is the researcher a friend, counsellor or ‘objective’ observer?

(Rogers and Ludhra, 2012: 43).

### *Initial themes*

Sherrie and I had research meetings about what we considered to be the main issues that emerged from the data and building upon our interpretation the important themes to materialise were intimacy and friendships and ‘loss’ of friends and dreams (or expectations). The following sections are a result of discussing and interpreting these themes in the context of other research.

### **Intimacy and Friendships as a foundation to life and meaningful care**

Building upon what we have discussed above, and more generally in philosophical research, we find that people often want to be with other people (Arendt 1998, Stienstra and Ashcroft 2010), and need to be cared ‘for’ and ‘about’ at times throughout their lives (Kittay 2005, Lynch *et al.* 2009). To lack this relational interaction can be dehumanizing. Loneliness and emotional isolation is damaging to the essence of being human: to emotional and physical health (Pahl, 2000). This lack has been evidenced in research as individualism erodes humanity and caring spaces (Bauman 2003, Robinson 2011).

Without intimate friendship ties, it is often difficult to make sense of sexual and intimate identity as we found in interview data. Teela for example told us ‘I can talk to my mum about having a baby and everything’ but further explained, ‘I would like other girlfriends to chat to about sex, having babies and relationships’. Ben, when he was first experimenting with his sexuality found it difficult as he was worried his Mum would think he was ‘naughty’. Talking about coming out to his Mum, he said, ‘in a way I can understand why mum hit the roof coz obviously I’ve kept it a secret, but I just didn’t know what to say’. Ben encountered some hostility when he told his friends about being gay as he expressed here,

Yeah, a lot of my friends took offence by it, but I said to them, well if you don’t like it then you just best not to be friends with me, and I said it’s how I am, I mean (name)

fell out with me over it for a while (pause). Well I can understand his point, maybe he's a bit frightened that I'm going to do it to him, but obviously I won't coz I know he's not, but I know he was frightened, but after I told him and he got used to it he was all right, and I just said, "it's just how I am", he's got used to it now, but it was a shock to everyone'.

It is clear here in talking to Ben and Teela, as well as narratives from the focus group data having intimate friends is crucial in developing a healthy sense of sexual self-identity as well as being able to talk to someone about these sexual and intimate issues. These caring human relations are crucial for emotional health. Indeed, in the midst of cultural changes and the proliferation of social networking, the need to consider these aspects of human life for intellectually disabled people is a matter of urgency, especially as de-institutionalisation and community care projects have developed. As a matter of fact, Shakespeare (2006: 175) says 'disabled people are in the community, but not part of the community' (c.f. Johnson and Walmsley with Wolfe, 2010).

Undeniably it is the *human relations* aspects of social life that many intellectually disabled people talk about as Lafferty *et al.* (2013) demonstrate in their study concerning the meaning of close personal relationships. For example, social outings, becoming more socially involved, and being together, were prioritised as important. Our findings echoed this; Teela said that she wanted to 'see my boyfriend more often' and Ben explained that in his residential setting, 'they (the staff) won't let me go there on my own, they take me in the car, but the thing is I can't quite get why they won't let me go on my own. They let me go on my own (to the club) they drop me off and go, but they won't at (the pub)'. It is clear from other research and from our data that the problem of governance around intellectual disability is pervasive, and that maybe we need to think about how to do care differently while still caring, so as to 'ensure the flourishing of all persons' (Robinson 2011: 33).

Other themes of sociability and personal relationships were highlighted when participants were asked 'why join the focus group?', as our field notes show;

*The opening question was very broad, 'so why did you decide to get involved in this research?' Ben piped up 'I want to learn a lot from this experience, I really think I'm going to learn about friends and relationships, I also want to make new friends'. 'I want to make new friends too' chipped in Teela 'especially female ones so that I can talk about things girls talk about'. 'I'd like to make more friends, but I also really*

*want to spend more time with my boyfriend' Kerry exclaimed. George agreed with the group saying he wanted to make new friends, but actually saw this group as a way also of getting to know those he knew already a little better.*

Despite the focus group being promoted as sexuality and relationships research many of the participants spoke about transport (to go to and from meeting with friends), money, (to enable social interaction), being with friends and boyfriends (or not spending enough time with them) and talking about the future (getting married and having a family), confirming the importance of simply being with others to chat to and have intimate conversations with. While the participants did not really identify these areas as relationship and intimacy discussions, clearly they involve being with people, enabling social intimacy or reflecting on future relationships. These themes are played out in other intellectual disability research, for example, in Hollomotz's (2011) on sexual vulnerability and Taylor Gomez's (2012) on sexuality, sensuality and sexual expression.

Sex, social justice and caring practices were also important, particularly when discussing marriage and reproduction. Shakespeare (2006) has reflected upon disability and sexuality literature in response to the changing social and cultural context of intimacy and how humans relate to each other. He reveals how crucial friendships networks are as,

A century ago, we would have been socially and culturally determined by our family. Fifty years ago, this role would have been played out by our work and career. Now it is the people we do things with that count. Developing rich and varied social connections and having friends is a hidden but vital dimension of society (*ibid*: 170).

Drawing on the work of Pahl (2000) he suggests that humans not only need to access material resources but also psychological ones to be fully involved in society. Having friends and caring relationships, and being able to choose who we socialise with is critical in human life. For intellectually disabled people they do not necessarily have the 'freedom' to choose and consider life paths about career options and friendship networks due to social constraints or intellectual impairment.

For our participants being restricted in daily life was the norm. Kerry told us 'my boyfriend's parents have learning difficulties which prevents me from seeing him'. George said, 'as I am in supported living I often have to wait for staff availability to even go out'. Putting friendships and relationships on the political map for intellectually disabled people is a vital

part of our research agenda. Sociability, getting out and about and making friends is important in caring relations.

### **‘Losing’ friends and dreams**

Henderson and her colleagues (2007) found generally young people’s imagined futures involve long term relationships and children. But for intellectually disabled people ‘[e]ven where disabled people have friends and companions, they may find it harder to experience everyday intimacies’ (Shakespeare 2006: 173) and therefore fracture their expectations and dreams. In Hollomotz’ (2011) research, losing friends or not having friends in the local community is often due to services and education provision being ‘somewhere else’ or changed without consultation. For example in her research, Rose one of Hollomotz’ participants tells her about a friend who loses touch with her boyfriend through no fault of her own. Rose said her friend ‘attends a different day service venue since her day service was reorganised. She has not seen him since and she has no means of keeping in touch with him’ (2011: 92). This is not an isolated case. People who are deemed cognitively able would not have this type of restriction imposed upon them. If, for example a non-intellectually disabled person was to change geographical location they may well remain friends with others by choice and through different social media. The same cannot necessarily be said for intellectually disabled people. This transient and fractured nature of friendships is not one that is chosen, nor is it even considered by many staff or broader socio-political directives. This careless space and systemic violence where friendships and intimate relationships are considered meaningless, movable and inconsequential is dehumanizing.

This can be seen clearly throughout Hollomotz’ (2011: 63) research as with Rose, in her narratives about the reorganisation of day services, and as in our research with restrictions on social life due to staff availability. The more nuanced symbolic violence where hopes and dreams for the future are no different to many other people can be seen. Furthermore, Hollomotz’ (2011) participant Tyler talks about the desire to have what many others have and wants ‘nothing more than a long term relationship’, and continues,

I’ve always had this dream. I’m sat on the settee with my girlfriend in my arm and my child playing at the table and I’m watching television... and I wake up with a smile on my face and a very warm feeling. I go: ‘that’s what I want’ (*ibid*: 63).

These narratives about hope and desires for intimacy and life with a partner are evident in Hollomotz' (2011) research, but are also demonstrated in personal narrative data where Sherrie reflects upon her aspirations to marry and have a family.

With support, Sherrie reflects on an everyday desire that many other young people dream about.

*Today is like any other day for Mum (out of term time). She had a cup of tea and cereal, helped me wash my hair in the bath and began to think about what writing she had to do. She wandered into the living room, and my pile of cut outs and Argos books (similar to mail order books) are stacked up on my sofa. A note book open at a page with copied words. Mum shouts up the stairs, "Sherrie can we throw out the old Argos book (a catalogue with all types of goods for sale - clothes, electrical equipment, jewellery, and so on) and some of these scraps?" The terror in my voice can be heard as I run down the stairs screaming "NO!" "But they are old and an unsightly mess. Please just some of it then" she pleads. But no, not today – not ever.*

In a research meeting we contemplated this conversation. Why is the Argos book so desperately important? Sherrie cuts out pictures from the book everyday - pictures of funky kettles and toasters, white goods, cots, beds, wardrobes and pictures of wedding rings, engagement rings and other wedding related paraphernalia. In the UK, traditionally some of these items might have been called 'bottom drawer items', (goods that young women often collected for married life). Sherrie's desire and expectation for what she wants in life, as well as the desire of others in the research, for example, both Teela and Ben said they wanted long term partners, and the focus group data storied similar narratives, is no different to other non-disabled young people. Henderson *et al.* (2007) found almost all young people imagined they would be married or in long term partnership with children by the time they were 35. Their imagined life course and their actual biography did not always tally, but still the research narratives show this is a culturally imagined future for many young people.

As it is many intellectually disabled people want to have relationships yet human interaction, the emotional connection and the everyday aspect of being with people is less secure for them (see Kittay and Carlson 2010, Robinson 2011). Simply put many moderately to severely intellectually disabled people do not have the same opportunities to meet people at work and socially. One of the contentious issues for intellectually disabled people is due to their intellectual impairment they are infantilised, or assumed as less than human, on the basis of

their perceived and actual vulnerability (Hollomotz, 2011) and their best interests, (HMSO, 2005). These issues directly impact upon their maintaining or losing intimate and friendship relations as we have explored here. Furthermore, maintaining friendships and intimacy is crucial, and this is in part the responsibility for those who are in caring relations, paid or otherwise, but also the responsibility of the socio-political sphere to promote and enhance careful spaces.

### **Concluding remarks**

Sometimes intellectually disabled people do not understand the social or cultural context within which they live, and it is down to caring work and care-full relations to mediate such intimacies. Furthermore, intellectually disabled people do not inhabit one culture, country, ethnicity, sexuality or class for example, yet they will always be interdependent and in relationships. The emotional, practical and socio-political caring spheres identified offer ways into thinking through a care ethics model of disability, in understanding being human, when reflecting upon relationships for intellectually disabled people and research processes. For the purposes of considering intimacy, friendship, and intellectual disability, the emotional and moreover, psycho-social lie at the heart of relations, the self and a care ethics model. It is here we wonder how the self exists in relation to another in particular circumstances and how a care ethics model of disability might support careful relations. Are caring and care-full relations always about reciprocity, friendships and intimacy and how are they managed when evidently what we often consider as private feelings and actions are made public and are then be interpreted by others? Intimacy and relationships for intellectually disabled people has been storied in a way that is beyond caring and friendship and is indeed careless. Often described as unable, unwilling, too willing, uncaring, not worthy; intellectually disabled people have been left without care, lonely and dehumanized.

It is clear intimate relationships and friendships benefit the everyday and how they can positively promote carefulness across all three caring spheres. It is also evident that intellectually disabled people might not always understand the meaning of the injustices that are perpetrated against them (even while they experience these), so it is essential we continue to research within a care ethics model (Rogers in press), and in an inclusive manner where it is appropriate (Johnson 2009, Nind and Vinha 2012, Walmsley and Mannan 2009). This might mean we do not always want to dis-identify those contributing to the research as

participants (Manning 2009), or to eliminate narratives from non-disabled people who live with disability (Hillyer 1993: 107 (*c.f.* Gurol *et al.* 2014, Shakespeare 2006, Walmsley 2004).

As non-disabled and disabled researchers we recognise that our interaction with our data, our relations with everyday disability issues and our personal relationship as mother and daughter have an impact upon how we understand the world around us, but that does not mean we ought not to continue. The challenge for us as researchers is when ‘those in power make decisions based on attributes such as rationality, language, roughly equal physical and mental capacity, as rudiments for participating in citizenship’ (Nussbaum, 2006: 16). This clearly excludes many intellectually disabled people from contributing to and participating in civil society and indeed in research. It is therefore important to pursue co-constructed research. Sherrie has not fully understood in any traditional sense, all the theoretical conceptualisation and literature discussed, but we have carried out meaningful and careful research meetings that covered all the issues in this paper in attempting to think about intimate relationships and friendships as part of being human. For intellectually disabled people the management of personal relations is often overseen by professional carers, mothers/fathers, or other family members (Foley 2012, Hollomotz 2011, Rogers, in press, 2013, Shakespeare 2006). This moral, ethical, practical and political dilemma necessitates further action (Kittay and Carlson 2010) as a ‘radical reconceptualization of the public-private dichotomy’ needs commitment (Robinson, 2011: 31) in order to see and promote the *socio-political* as an all-encompassing ‘care space’. We need to keep sex and intimacy research on the agenda, yet also find ways of doing research in a meaningful, caring and co-constructed way.

### **Acknowledgements**

I would like to thank the Childhood and Youth Research Institute at Anglia Ruskin University for funding the project that part of this paper draws upon and all those who participated in the research. I would like to thank Eamonn Carrabine and Katherine Runswick-Cole, as well as the anonymous reviewers for giving me some critical comments to work with and move the paper forward. It is much appreciated. Last but not least, huge thanks to Sherrie my co-researcher for making me look at things differently – always.

### **References**

Adler, P. and Adler, P. (1997) ‘Parent-as-Researcher: The Politics of Researching in the

- Personal Life' in R. Hertz, (Ed) *Reflexivity and VOICE* London: Sage Publications
- Arendt, H. (1998 [1958]) *The Human Condition* London, The University of Chicago Press
- Bauman, Z. (2003) *Liquid Love: On the Frailty of Human Bonds* Cambridge, Polity Press
- Booth, T. and Booth, W. (1998) *Growing up with parents who have learning difficulties* London, Routledge
- Boxall, K. and Ralph, S. (2010) 'Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research' *British Journal of Learning Disabilities* 39: 173-180
- Cooper, L. and Rogers, C. (2015) 'Mothering and 'insider' dilemmas: Feminist sociologists in the research process' *Sociological Research Online* 20 (2) 5
- Davis, L. J. (2006) (ed). 'Constructing Normalcy: The Bell Curve: the Novel, and the invention of the Disabled Body in the Nineteenth Century' in L.J. Davis, *The Disability Studies Reader (2<sup>nd</sup> Ed)* Oxon, Routledge
- Duncombe, J. and Marsden, D. (1993) 'Love and Intimacy: The Gender Division of Emotion and 'Emotion Work': A Neglected Aspect of Sociological Discussion of Heterosexual Relationships' *Sociology* 27 (2) 221-241
- Foley, S. (2012) 'Reluctant 'jailors' speak out: parents of adults with Down syndrome living in the parental home on how they negotiate the tension between empowering and protecting their intellectual disabled sons and daughters' *British Journal of Learning Disabilities* 41 304-311
- Gabb, J. (2008) *Researching Intimacy in Families* Houndmills, Palgrave Macmillan
- Gillespie-Sells, K., Hill, M. and Robbins, B. (1998) *She Dances to Different Drums: Research into disabled women's sexuality* London, Kings Fund Publishing
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, Penguin Books
- Groner, R. (2012) 'Sex as "spock": Autism, Sexuality, and Autobiographical Narrative' R. McRuer and A. Mollow [eds.] *Sex and Disability* London, Duke University Press
- Guroi, A., Polat, S. and Oran, T. (2014) 'Views of Mothers Having Children with Intellectual Disability Regarding Sexual Education: A Qualitative Study' *Sexuality and Disability* 32: 123-133
- Held, V. (2006) *The Ethics of Care: Personal, Political and Global* Oxford, Oxford University Press

- Henderson, S., Holland, J., McGrellis, S., Sharpe, S. and Thomson, R. (2007) *Inventing adulthoods: a biographical approach to youth transitions* London, Sage Publications
- Herring, J. (2013) *Caring and the Law* Oxford, Hart Publishing Ltd.
- Hillyer, B. (1993) *Feminism and Disability* London, University of Oklahoma Press.
- HMSO (2005) *Mental Capacity Act 2005* UK, Her Majesty Stationary Office
- Hollomotz, A. (2011) *Learning Difficulties and Sexual Vulnerability: A Social Approach* London, Jessica Kingsley Publishers
- Johnson, K. (2009) 'No Longer Researching About Us Without Us: a researcher's reflection on rights and inclusive research in Ireland' *British Journal Of Learning Disabilities* 37: 250-256.
- Johnson, K. and Walmsley, J. with Wolfe, M. (2010) *People with Intellectual disabilities: Towards a good life?* Bristol, Policy Press
- Kelly, G. Crowley, H. and Hamilton, C. (2009) 'Rights, sexuality and relationships in Ireland: 'it'd be nice to be kind of trusted'', *British Journal of Learning Disabilities* 37: 308-315
- Kim, E. (2011) 'Asexuality in disability narratives' *Sexualities*, 14 (4) 479-493
- Kittay, E. F. (2005) 'Dependency, difference and the Global Ethic of Care', *Journal of political Philosophy*, 13(4): 443-469.
- Kittay, E. F. and Carlson, L. (2010) (eds.) *Cognitive Disability and its Challenge to Moral Philosophy* West Sussex, Wiley-Blackwell
- Lafferty, A, McConkey, R. and Taggart, L. (2013) 'Beyond friendship: the nature and meaning of close personal relationships as perceived by people with learning disabilities' *Disability and Society* 28 (8) 1074-1088
- Lundy, L., McEvoy, L. and Byrne, B. (2011) 'Working With Young Children as Co-researchers: An Approach Informed by the United Nations Convention on the Rights of the Child', *Early Education and Development* 22 (5) 714-736
- Lynch, K., Baker, J., and Lyons, M. (2009) (eds.) *Affective Equality: Love, Care and Injustice* Houndsmill, PALGRAVE MACMILLAN
- MacLeaod, A. G., Lewis, A. and Robertson, C. (2013) "'CHARLIE: PLEASE RESPOND!'" Using a participatory methodology with individuals on the autism spectrum', *International Journal of Research and Method in Education* DOI: 10.1080/1743727X2013.776528

- Manning, C. (2009) 'My memory's back!' Inclusive learning disability research using ethics, oral history and digital storytelling' *British Journal of Learning Disabilities* 38 160-167
- McClimens, A. (2007) 'This is my truth, tell me yours: exploring the internal tensions within collaborative learning disability research' *British Journal of Learning Disabilities* 36: 271-276
- McCarthy, M. (2009) "I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities' *Women's Studies International Forum* 32, 198-208
- McCarthy, M. (2010) 'Exercising choice and control – women with learning disabilities and contraception' *British Journal of Learning Disabilities* 38, 293-302
- Nussbaum, M. C. (2006) *Frontiers of Justice: Disability, Nationality, Species Membership*, USA, First Harvard University Press
- Pahl, R. (2000) *On Friendship*, Cambridge, Polity Press
- Pfeiffer, D. (2006) 'Eugenics and disability discrimination', in L. Barton (ed.) *Overcoming Disabling Barriers: 18 years of Disability and Society* London, Routledge
- Rabinow, P. (1984) [ed.] *The Foucault Reader* Harmondsworth, Penguin Books
- Ribbens, J. and Edwards, R. (1998) (Eds.) *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives* London: Sage Publications.
- Richards, D., Watson, S.L., Monger, S., and Rogers, C. (2012) 'The Right to Sexuality and Relationships' in F. Owen, D. Griffiths, & S. Watson [eds.], *The Human Rights Agenda For Persons With Intellectual Disabilities*, New York, NADD Press.
- Robinson, F. (2011) *The Ethics of Care: A feminist approach to human security*, Philadelphia: Temple University Press
- Rogers, C. (2007) *Parenting and Inclusive Education: discovering difference, experiencing difficulty* Basingstoke: Palgrave Macmillan
- Rogers, C. (2009) (S) excerpts from a life told: sex, gender and learning disability in *Sexualities* 12 (3), 270-288.
- Rogers, C. (2010) 'But it's not all about the sex: mothering, normalisation and young learning disabled people', *Disability and Society* 25 (1) 63-74
- Rogers, C. (2013) 'Intellectual disability and mothering: an engagement with ethics of care and emotional work' in C, Rogers and S, Weller [eds.] *Critical Approaches to Care: Understanding caring relations, identities and cultures* London, Routledge
- Rogers, C. (in press) *Intellectual Disability and Being Human: A care ethics model* London,

- Rogers, C. and Ludhra, G. (2012) 'Research ethics: participation, social difference and informed consent' in S, Bradford and F, Cullen [eds.] *Research and Research Methods for Youth Practitioners*, London, Routledge.
- Runswick-Cole, K. and Goodley, D. (2013) 'Big Society? Disabled people with learning disabilities and civil society' Paper presented at University of Southampton, November, 2013.
- Ryan, S. and Runswick-Cole K. (2008) 'Repositioning mothers: mothers, disabled children and disability studies' *Disability and Society* 23 (3), 199-210.
- Shakespeare, T (2006) *Disability Rights and Wrongs* Oxon: Routledge
- Shildrick, M. (2009) *Dangerous Discourses of Disability, Subjectivity and Sexuality* Houndmills, Palgrave Macmillan
- Sakellariou, D. (2012) 'Sexuality and Disability: A Discussion on Care of the Self', *Sexuality and Disability* 30: 187-197
- Siebers, T. (2012) 'A sexual culture for disabled people', in R. McRuer and A. Mollow [eds.] *Sex and Disability* London, Duke University Press
- Spencer, L. and Pahl, R. (2006) *Rethinking Friendship: Hidden Solidarities Today* Woodstock, Princeton University Press
- Taylor Gomez, M. (2012) 'The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability, *Sexuality and Disability* 30: 237-245
- Tronto, J. (2011) 'A feminist democratic ethics of care and global care workers' in R. Mahon and F. Robinson (eds) *Feminist Ethics and Social Policy: Towards a New Global Political Economy of Care* Canada, University of British Columbia Press.
- United Nations (2006) Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Walmsley, J. (2004) 'Inclusive learning disability research: the (non-disabled) researcher's role' *British Journal of Learning Disabilities* 32: 65-71
- Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures* London: Jessica Kingsley Publishers
- Walmsley, J. and Mannan, H. (2009) 'Parents as co-researchers: a participatory action research initiative involving parents of people with intellectual disabilities in Ireland' *British Journal of Learning Disabilities* 37: 271-276