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## INTRODUCTION

### INTELLECTUAL DISABILITY AND SEXUALITY: ON THE AGENDA?

[P]hilosophical questions that emerge in connection with intellectual disability are matters that not only are worthy of scholarly interest but speak to the deepest problems of exclusion, oppression, and dehumanization; [...] one's proximity to persons with intellectual disabilities should be neither assumed as a basis for participation in this conversation nor grounds for disqualification when speaking philosophically about this topic (Carlson, 2010: 3).

Licia Carlson arouses an interesting starting point in thinking about connections to or with participants in research, especially intellectually disabled people. This special issue really does draw out this aspect of distance to and from those we research, within the substantive area of sexuality and intimacy. Largely because what is common, is that all the researchers involved here have a committed connection to understanding intellectual disability and then telling their story in different ways. They have worked with, researched with, or spent many hours with intellectually disabled people. For example, Feely, has worked in the field of counselling and intellectual disability for many years, Turner and Crane are therapists working with intellectually disabled people, Rogers with Tuckwell write as a non-disabled mother and her intellectually disabled daughter, and Fish has spent many hours on a locked ward with intellectually disabled women. But Carlson suggests also that close proximity to intellectual disability in a familial or relationship sense does not give exclusive rights over speaking out about intellectual disability. Banks, and Ledger and her colleagues write their research from a marginal position, (to an extent), and yet both the qualitative (Banks) and quantitative research (Ledger *et al*), address sexuality issues appropriately in pushing forward the agenda on how support workers manage their emotions around sexuality and relationship issues (Banks) and reproductive rights (Ledger *et al*).

Not only in this special issue do I bring together those who are working closely with, have a personal connection to, or want to make changes for, intellectually disabled people, this volume is pluralistic, in the sense that, no one way is the right way in understanding sexuality, sexual health and intimacy for intellectually disabled people. Yet we might find we are,

[o]bscured by the limits of our own small worlds, we find it so very hard to grasp the plural worlds of others; and to recognize that although they are not quite the same as ours, we are surely all bound by a common humanity. We are blinded by the restriction of our little-minded parochialism, provincialisms, patriotism and patriarchalisms. Usually we do not even see this, let alone try to move beyond. [...] We stigmatise, silence and ultimately slaughter those others who, in their millions, are not like us, those others who render vulnerable the safety of our world, those who become our enemies (Plummer, 2015: 15).

Ken Plummer is writing within the context of cosmopolitan sexualities in this quotation, but I consider this frame enlightening in discussing sexuality, intimacy and intellectual disability, not least because those who are different are considered a danger to the social fabric of society, or are in danger themselves. This is because, normativity is all around us, and as O'Neill, (1996: xi) remarks we 'not merely have desires: we claim that we and others ought to act on some of them, but not on others. We assume that what somebody believes or does may be judged

reasonable or unreasonable, right or wrong, good or bad, that it is answerable to standards or norms'. We are condemned for behaviour that falls outside of what is culturally expected.

As it is, particular features of social life for intellectually disabled people are detailed in this volume through methodological and theoretical discussion as here we come to position intellectually disabled people at the centre of an agenda where their bodies, lives and rights to have a sexual, relationship and intimate life are critically examined. What we discover is that sexuality and relationships and pleasure and intimacy are characteristics of human life. These might change and develop through having control, or not, over a number of aspects of life, such as, reproductive life and the body, social and geographical mobility, dating and leisure and emotions and relationships. Moreover, despite the fact that Michelle McCarthy, Kelley Johnson, Margrit Shildrick and Tom Shakespeare (and a number of others, all identified in this volume), have brought to light crucial issues to do with disability and sexuality, reading the papers based on research in this special issue, we clearly see there is some way to go in making a mark and setting the sexuality agenda for and with intellectually disabled people. It is also evident in sexuality research generally there has not been enough work when it comes to intellectual disability and relationships, the importance of friendships (intimate or otherwise) and we have not gone far enough in understanding reproductive control, or pleasure. Furthermore, little research has been carried out in restricted institutional settings, and those who work with intellectually disabled people have not told their stories about sexuality and intimacy. All these areas are covered.

Banks for example, writes about one story, drawn from a larger project in an Australian city. It is about Vic, a support worker, and about one incident that he had to deal with – a relationship break up. Vic's usual position as taxi driver, or the protector of/ protector from perceived risk mediated a relationship between Ellie and Tim; two intellectually disabled adults. He would drive Ellie to Tim's and then onto a café/restaurant/cinema. He would sit apart from them, and as Banks puts it, act as a border control agent, limiting bad happenings. But one night Tim, at his front door said to Vic when he went to pick him up, he no longer wanted to see Ellie, and shut the door. That was that. Vic's minor role in the story as mediator/facilitator turned into one of the main characters. He was thrown into feeling and recognising the pain, and sometimes discomfort of being disabled. What many experience as a private affair (a break up) was public. In addition to that, Vic was no longer a surveyor, but part of the surveyed. He was dining at the table with an emotional lady where others looked on. Banks uses Axel Honneth's notion of recognition and Arlie Hochschild's account of feeling rules to explore the immensely emotive shifts in how Vic attempts to grapple with his agency as a worker managing emotions, as a confidante listening and as a human being in understanding loss – in the midst of a break up.

Thinking about the emotional and close relationship between support worker and service user we might begin to explore a commonality with Rogers with Tuckwell – that of expectation of intimacy and relationships. Vic as a support worker did not expect Ellie and Tim's relationship to end, and certainly he did not expect to get emotionally involved. But we find that in Rogers with Tuckwell's research not only that Rogers is very much involved in Tuckwell's life, wishes and desires, but the human aspect of friendship and intimacy is a pleasure often denied to many intellectually disabled people. The assumed position of a relationship norm, and then how the loss of that (whether real, or imagined is played out) is investigated. In their paper they find that from qualitative research, young intellectually disabled people do not often get what they desire, for example, love, marriage and friends. Importantly, in their co-constructed research they found that young intellectually disabled people feel lonely and want relationships just like their non-disabled peers. But that they do not have the same social or geographical mobility.

They particularly explore being human and find reproduction and sex alone is not enough. In being human, they suggest a need to have some kind of relational interaction and emotional connection. They also advise that sex and intimacy research remain on the agenda, but also find ways of doing research in a meaningful, caring and co-constructed way, within a care ethics model of disability.

Turner and Crane's contribution is largely about pleasure and intimacy and in a sense what realistic representations of sexuality and pleasure amounts to for intellectually disabled people. The core themes to come from this case study with 5 adults are sensuality (physical pleasure) and intimacy (emotional pleasure). It seems pleasure for intellectually disabled people is widely derided due to their assumed angelic or devilish nature. This is not unusual as the 'childlike' or 'predatory' intellectually disabled adult is positioned as weak, vulnerable, morally fractured, lascivious and so on. The strength of Turner and Crane's research is in connecting professional practice with academic rigour and then making policy recommendations. Drawing on research in therapeutic practice is not dissimilar to how aspects of Craib's (1994) work panned out. He, as a social theorist as well as a practicing psychotherapist was able to weave stories from the therapeutic field into his sociological work that opened up deeper understandings of human interaction. Importantly Turner and Crane reveal that focussing on a pathological or crisis framework of sexuality for intellectually disabled people is a constant negative. They liken it to preparing for a holiday and then only concentrating on difficult family relationships, economic cost, stress – all of which might come into play, but we ought not to focus on this. Pleasure should be a priority.

Yet as we understand with sexual pleasure for intellectually disabled people, along comes surveillance and governance. Picking up on the aspect of surveillance and control Fish's ethnographic research uncovers that intellectually disabled women on locked wards are often considered both vulnerable and dangerous. Indeed their vulnerability is used as a regulatory tool so as to exert control over their 'difficult behaviour' in keeping them separated from men as well as surveyed so closely many are unable to pursue individual sexual gratification. Moreover, those who do show signs of sexual need/desire are considered promiscuous. Remarkably, what we discover in Fish's work is that even if a woman wants same sex relations, or tells someone she is gay, this is often considered as a result of an abusive and violent past at the hands of the men in their lives. One young woman was excluded from an LGBT group because she was told she was 'too young' at 19. In the case of sexuality, when it came to discussing issues with trained therapists, sexuality and in one case bi-sexuality was considered a 'special issue' and therefore needed to be passed on to someone with more 'expertise'. This is when other research such as Turner and Crane's might come in useful in thinking through training needs, for particular client groups, but more important, we need to consider the fact that sexuality is not a special issue in the first instance. What we recognise here is that surveillance and control is rife, and not always in the best interests of the women.

Feely too identifies control and surveillance as an overarching issue, as he carried out qualitative research in Ireland. Like with discourses around religion he sees that discourses of vulnerability and abuse affect the sexual lives of intellectually disabled adults. This is important as we discover, for example that one support worker, has to follow a female service user around (even to the toilet at parties) after a sexual encounter between this woman and an intellectually disabled man was deemed inappropriate. In another story Feely explores the nature of entrapment, where an intellectually disabled man who was considered as acting sexually inappropriately in public with women was heavily surveyed. These examples and others, enable Feely to disentangle the flow of data that is shared between families, staff, police, and

other service users in a way that suggests sexual surveillance is complicated as he uses a Foucauldian and Deleuzian lens to understand sexuality and social control. But social control is not just about how we understand it in Feely's interpretation.

Ledger and her colleagues research is based on a survey that uses a small convenience sample with learning disability nurses, support workers, family members (mostly mothers), advocates, doctors amongst others. It clearly sets up the research within a socio-historical context using a plethora of relevant studies. Although it seems many intellectually disabled women do have the capacity to conceive children, many do not have the control over their own decision making process. Indeed only a minority (14%) in their sample made their own decision about contraception and in the main ultimate decisions were made by the doctor or mother. What was most concerning to Ledger and her colleagues was that a significant reason for contraception was not only about pregnancy avoidance and control of menstrual cycle, but to avoid abuse, and yet as we discover from other research they draw upon, contraception has been used as a way of *maintaining sexual abuse*. Clearly there are many more issues that the paper draws out, such as problems with access to clear information about contraception in the form of easy-read format, and how reproductive capacity is managed overall, but the main point to draw on is that despite on-going research in the area of contraception and reproduction for intellectually disabled women, there are gaping holes between policy and practice, particularly for those women with severe and profound intellectual impairments.

The articles in this special issue were not commissioned, but were put together as a result of a call on 'Intellectual disability and sexuality', so all the authors had their own motivations in carrying out their research and deciding to be a part of this special issue. My motivation came about as a result of personal experiences as a mother with an intellectually disabled adult daughter, and then talking with her about sexuality issues, (and subsequently doing research with her), writing about this area of intimacy and sexuality and carrying out a small scale project with young intellectually disabled adults. The impetus also came about as a result of reading research that is about disability and sexuality generally. There are indeed important issues to discuss around physical disability and sexuality, nevertheless there are particular concerns that surface when someone has an intellectual impairment. Not least of all the infantilisation, governing and representation of intellectually disabled people. And this is because throughout time intellectually disabled people have caused more than a little concern for the legal system, policy makers, politicians, social cohesion and reproduction, and the vitriol that has been levied at them, and about them, in the past century is evident.

Indeed we do not have to go too far to evidence this as Pfeiffer (2006) draws on the likes of Havelock Ellis who led in areas of human rights (yet was a promoter of eugenics) and Walter Fernald, who was the successor to Howe (who founded the Massachusetts School for Idiotic Children) to make a point about this malice. He quotes Ellis as saying "feble-minded" people "an evil that is unmitigated", a 'poison to the race, and their "very existence is itself an impediment" to civilization' (Pfeiffer, 2006: 83) and he goes on to quote Fernald who said in the early 20<sup>th</sup> century,

[t]he feble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. [...] It has been truly said that feble-mindedness is the mother of crime, pauperism and degeneracy. [...] The most important point is that feble-mindedness is highly hereditary. [...] No feble-minded person should be allowed to marry or become a parent. [...] Certain families should become extinct. Parenthood is not for all' (*ibid*).

These quotes from the early 20<sup>th</sup> century are not too dissimilar to some of the remarks levied at intellectually disabled people in the current news, from rights to earn a viable living (Withnall 2014) to whether or not they ought to be born (Walker and Quinn 2012). What the papers in this special issues do is credibly and necessarily address social issues, policy and practice in pushing forward the agenda on sexuality ‘for’ and ‘with’ intellectually disabled people.

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