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<http://dx.doi.org/10.1108/TLDR-01-2017-0002>

Title	More than pictures : who sets the agenda for sexuality education for people with learning disabilities?
Authors	Olsen, AM
Type	Article
URL	This version is available at: http://usir.salford.ac.uk/id/eprint/41494/
Published Date	2017

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JOURNAL: Tizard Learning Disability Review
VOL/ISSUE NO: 22/2
ARTICLE NO: 591980
ARTICLE TITLE: More than pictures: who sets the agenda for sexuality education for people with learning disabilities?
AUTHORS: Angela Olsen

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Commentary

More than pictures: who sets the agenda for sexuality education for people with learning disabilities?

Angela Olsen

Abstract

Purpose – *The purpose of this paper is to provide a commentary on Cameron and Matthews' paper "More than pictures: developing an accessible resource".*

Design/methodology/approach – *It reflects on how much people with learning disabilities are involved in research and resource development and how the attitudes of caregivers impact on how people learn about sexuality.*

Findings – *Most published research is written by people who do not have learning disabilities but people with learning disabilities are taking part in research and they are making changes to the way things happen. Parents, educators and caregivers are often reluctant to discuss sexuality with people with learning disabilities and this affects how much people can understand about it.*

Originality/value – *This paper argues for greater involvement of people with learning disabilities in research processes.*

Keywords *Human rights, Co-production, Inclusion, Sexuality, Accessibility, Social construct*

Paper type *Viewpoint*

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Cameron and Matthews state that one of their reasons for writing their "More than pictures" paper was to explain how the resource was developed. They describe the development of the Talking Mats resource as an iterative process involving a fairly large number of personnel, mainly practitioners and designers. People with learning disabilities were involved in the development as testers of the product, responding as users of the resource during the trial period. This inclusion of people with learning disabilities as testers of an emerging product raised within me some interesting points for personal reflection.

These are:

- To what extent are people with learning disabilities contributing to research and the development of resources?
- How the attitudes of caregivers might influence the development of sexual rights for people with learning disabilities?

To what extent are people with learning disabilities contributing to research and development?

The Care Act (2014) required local authorities to promote the well-being of adults in each authority area and placed upon them a duty to provide information that is accessible and proportionate to the

needs of the people who require it. Similarly the Accessible Information Standard states that from 31 July 2016 all organisations that provide NHS care or adult social care (in England) are legally required to provide accessible information (information which is able to be read or received and understood by the individual or group for which it is intended), and communication support (support which is needed to enable effective, accurate dialogue between a professional and a service user to take place) for people with disability, impairment or sensory loss (NHS, 2015).

While this requirement has resulted in some changes, e.g. pictures can now be seen alongside words on some hospital literature and social care services office notices, what is less clear is who decided whether or not the chosen pictures or images are effective.

Unfortunately, not all service providers value the input of potential service users, believing that they can adapt existing information quickly and cheaply by using generic images found online. What this approach fails to understand is that accessibility of information is not simply about adding pictures. Involving service users, including people with learning disabilities in initial discussions about service structure, important information and learning about their understanding of barriers to accessibility, is crucial to the development of any new resource that purports to be to their benefit.

Organisations such as CHANGE and Vision Sense are user-led organisations, where people with learning disabilities are true consultants to large organisations. In these organisations people with learning disabilities not only review the information that the organisation is considering making accessible but they also comment on other aspects of services that might impact accessibility and well-being, such as the need for pedestrian crossings close to buildings, signage, websites and telephony.

Twenty-five years ago Oliver (1992) called for paradigm shift in research proposing an “emancipatory” paradigm, which would see research being directed by and for people with disabilities. It is not always straightforward to define emancipatory research. I consider below three apparently strong examples where the research was carried out through a process of co-production and people with learning disabilities were equal partners. Undoubtedly, there are other examples but it remains the case that still relatively few researchers invest in this approach.

A request to colleagues regarding whether they knew of examples of co-production or real partnership in the development of resources identified a number of resources produced by local learning disability practitioners and service user groups. These resources, often developed in response to issues identified by service user groups, tended to meet local need and remain unpublished. Readers will no doubt be familiar with similar developments in their own localities. While these local developments are to be celebrated for their emancipatory approaches such unpublished resources are “lost” to the wider audience.

When questioned about lack of publication our practitioner colleagues cited lack of time and fear of being unable to write to an acceptable academic standard as reasons for keeping their work local. It remains of course unclear whether in fact these resources would have wider relevance, as it is possible that they will have been made accessible to those local groups (as symbols, etc., will have been made to make sense to the co-producers) but their wider impact remains untested. For those who do publish research and development projects, the factor that sets them apart from the rest is the way in which the voices of the researchers with learning disabilities are presented. White and Morgan (2012) appear to be written in the voice of Emma White, a woman with Down syndrome who describes her journey towards becoming a true research partner, rather than a consultant after the fact. White explains that she was introduced to research in a university by Morgan, her research partner who was undertaking her PhD. White describes the importance of feeling the same as other researchers, wearing the “university shirt”, having access to lectures, the library and the mailroom, learning the difficult long research jargon, etc.; in fact all of the things that signify belonging to the university, the things that research respondents or participants are usually excluded from. The paper demonstrates White’s full inclusion and the value that she brought to the research as a true partner. It clearly took time and effort by both research partners. Chapman *et al.* (2013) provide a learning disability perspective on “independence”. The paper takes the format of a focus group examination of aspects of independence. While it is an after the fact examination of an issue previously defined by others, it also provides a brief description of how the research group also acts as learning disability ambassadors raising awareness of learning disability issues in schools. In this



way the research partners can be seen to be setting the agenda for discussion. Finally, Olsen and Carter (2016) describe co-production of accessible literature for women with learning disabilities who have experienced sexual abuse. While the paper is written with an academic tone, it is clear that the work was led by the needs of the women with learning disabilities and that Carter, a woman with Down syndrome, was key to the success of the project due to her unique insight as a researcher who had also experienced abuse and was skilled in the development of accessible resources. What these papers have in common is the ownership of the research and resource development by people with learning disabilities.

How the attitudes of caregivers might influence the development of sexual rights for people with learning disabilities?

Cameron and Matthews (2017) commented that sex was the card that most people were reluctant to discuss. During the development of the Keeping Safe resource Cameron and Matthews trained 113 people to deliver the resource, with training lasting for one or two days. This level of training appears to have been effective as recorded in their impact analysis. The provision of training demonstrates good practice by ensuring that staff (listeners) know how to use the resource and how to support the thinkers (people with learning disabilities) to explore their thoughts and feelings when using the resource. One aspect of the report of the development of the resource that appears troubling is the response from staff that there was reluctance by professionals to discuss sex.

Such reluctance is well documented with many studies showing how lack of sex education may be a contributory factor in people with learning disabilities not recognising abusive relationships. The reluctance of parents, educators and other caregivers to provide useful information about sex and sexuality means that people with learning disabilities are often unsure about their own sexuality and lack understanding of safe sex practices (Bernert and Ogletree, 2013; Dukes and McGuire, 2009; Tullis and Zangrillo, 2013).



Löfgren-Martenson (2013) suggests that caregiver's attitudes towards the sexuality of people with learning disabilities are guided by two components:

- the belief that withholding sex education leads to protection from bad things happening, e.g. if we do not raise an expectation of a sexual encounter they will not have a bad experience; and
- disabled people's sexuality is different from "other" people's sexuality, i.e. "theirs" is unnatural and public and "ours" is natural and private.

These components are problematic for all concerned, the first because while it is understandable that any parent would want to protect their child from abuse it is also clear that education and information are important aspects of protection. Parents and caregivers must be encouraged to discuss sexual rights and responsibilities with people with learning disabilities. Second any practitioner who has participated in a multi-agency risk assessment to determine, for example, whether or not a 24-year-old woman with a mild learning disability can be "allowed" to entertain her 26-year-old boyfriend in the bedroom of her own tenancy can attest to the public nature of the sexuality of people with learning disabilities. However, while statutory agencies have safeguarding procedures requiring such public discussion fewer have guidance regarding the delivery of sexual rights education. Cameron and Matthews's respondents are not the only caregivers who are reluctant to talk about sex. The private nature of "our" attitudes towards sexuality regularly takes precedence over the needs of others.

Sex research postulates that sex is a culturally specific social construct and that our understanding of sex is "scripted" for us; with Gagnon (1990, p. 5) stating that "sexuality is acquired, maintained and unlearned in all of its aspects and is organized by social structure and culture". In Western societies this means that for many people with learning disabilities the script includes an expectation that sex is a heterosexual act performed primarily for procreation. This is compounded by a received wisdom that people with learning disabilities should not become parents and leads many to abstain from sex rather than challenging the traditional, normative script and developing their own ideas of sexuality. For those for whom their first experience of sex was abusive and painful the thought of engaging in pleasurable sex is anathema (Bernert and Ogletree, 2013).

International studies indicate that people with learning disabilities are not seen as having a sexual identity in the same way as their non-disabled peers (McCarthy, 1999). Yet the World Health Organisation confirms that they should have the same sexual rights as their non-disabled peers.

“The application of existing human rights to sexuality and sexual health constitute sexual rights. Sexual rights protect all people’s rights to fulfil and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination” (World Health Organisation, 2010, p. 3).

Given that sexual rights should be available to all it is beholden upon caregivers to provide meaningful education to people with learning disabilities. It is unacceptable to collude with the notion of personal discomfort as an excuse for lack of engagement by people who are, after all, in positions of power and control over the well-being of others.

The knowledge and attitudes of sexuality educators, be they parents, school teachers or support workers, greatly influence the ability of people with learning disabilities to learn and understand their sexual rights (Bernert and Ogletree, 2013; Stoffelen *et al.*, 2013; Löfgren-Martenson, 2012; Löfgren-Martenson, 2013). A recent study in the Netherlands (Stoffelen *et al.*, 2013) discussed this theme with authors reporting some positive messages about staff engagement. Eight of the twenty-one research participants identified as homosexual were particularly positive about the support they received from lesbian or gay caregivers, stating that it made it easier for them to discuss “taboo issues relating to sexuality” (p. 261). The same paper reports dissatisfaction in circumstances where workers decline to discuss sexuality or only talk about it in a teasing way, asking about specific details in an apparently prurient manner.

All of the papers discussed in the preceding paragraph conclude with recommendations that consideration should be given to the training of caregivers in order that they can overcome shyness and reluctance to discuss sexuality with people with learning disabilities. The challenge to services is in understanding the competing norms and values of our multi-cultural society and ensuring that the norms and values of caregivers are not privileged over those of people with learning disabilities.

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Q2

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Further reading

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