Reducing the barriers to relationships and sexuality education for persons with intellectual disabilities

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Abstract

Opportunities for persons with intellectual disabilities to participate in relationships and sexuality education (RSE) are often constrained by the attitudes and perceptions of family carers, frontline support workers and professional staff. In order to understand how the barriers might be reduced, a study was undertaken in Northern Ireland with samples drawn from these three stakeholder groups, involving nearly 100 persons and using group and individual interviews. Although there was agreement on the need for RSE, four barriers were commonly reported: the need to protect vulnerable persons; the lack of training; the scarcity of educational resources; and cultural prohibitions. The impact of these barriers could be lessened through partnership working across these groups involving the provision of training and information about RSE, the development of risk management procedures and the empowerment of people with intellectual disabilities.

Keywords
family, intellectual disability, professionals, relationships, sex education

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Introduction

In recent years, there has been considerable societal and legislative progress internationally in tackling the obstacles experienced by people with intellectual disabilities with regard to education, employment and housing issues (Grant et al., 2010). Similar progress is less evident with respect to barriers experienced around relationships and sexuality. This is especially ironic given the high priority that people with intellectual disabilities place on having friends and a desire to be more knowledgeable about sexuality (Siebelink et al., 2006; Healy et al., 2009). In Northern Ireland, detailed interviews with 62 persons labelled as having 'learning disabilities'[1] aged 13 to 40 years identified marked gaps in their knowledge, with confusions evident in topics such as masturbation, pregnancy, contraception and sexually transmitted infections (Simpson et al., 2006). Moreover their experience of relationship and sexuality education (RSE) was vague or non-existent and 79 percent wanted to learn more. One young woman aged 25 commented:

> I think it has been ignored too long. People with a learning disability have the same rights as everybody else plus they need to know about sexual awareness, especially when you look at society, people with disabilities tend to be more vulnerable. (2006, p. 25)

Studies undertaken in other countries also confirm these findings (Griffiths et al., 2008).

The neglect of RSE contravenes the aspirations contained in international declarations of rights. For example:

> State parties should provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health. (UN Convention on the Rights of Persons with Disabilities, 2009, Article 25a)

In England, the Department of Health has set as a policy objective:

> People with learning disabilities have the choice to have relationships, become parents and continue to be parents, and are supported to do so. (2009, p. 92)

Nonetheless past research has documented the reticence among parents and service staff towards the provision of education about sexuality and relationships (McConkey and Ryan, 2001; Cuskelly and Bryde, 2004; Abbott and Howarth, 2007). In recognizing this, the *Valuing People Now* strategy identified that:

> Supporting people's rights to have relationships is mostly about challenging stereotypes and changing attitudes. (Department of Health, 2009, p. 93)

A step towards achieving increased opportunities for people with intellectual disabilities to access RSE is to have a better understanding of the influences that shape the perceptions of parents and service staff and to discover areas of consensus on which a common approach may be built.

Two major sources of influence can be readily identified. The first is the ethos of protection that surrounds persons deemed to be vulnerable. Although some attempts have been made to improve the equality of access for disabled people to opportunities that are readily available to non-disabled people, the notion of 'special needs' and 'protection' still leaves people with disabilities largely segregated from many activities in society. As Anderson and Kitchin (2000) argued, disabled people's lives are often portrayed as constrained and even deviant. Moreover the current provision and regulation of care services assume that people with intellectual disabilities need to be protected from abuse and they are presumed not to be capable of consenting to sexual relationships. Consequently the concepts of ‘special needs’ and ‘protection’ tend to be dominant and there is less concern for their legal and human rights.

A second major influence derives from the religious and moral climate of the society in which people live (McKelvey et al., 1999). In Northern Ireland, for example, sexuality can be a more sensitive issue than in other European countries, which can potentially militate against an open, honest acceptance and discussion of sex and sexuality (Rolsten et al., 2005). This conservatism with regard to sexual expression is particularly evident with regard to people with intellectual disabilities who are often perceived as perpetual children who need to be protected from sexual knowledge that may lead to inappropriate experimentation (Ryan and McConkey, 2000). As a result, education and support around sexuality and personal relationships have tended to be ignored, often to avoid personal embarrassment or disagreements among parents and professionals (Wolfe, 1997). Paradoxically this stance discounts the protection which knowledge about sexual behaviours provides to people who are vulnerable to sexual abuse (Murphy and O’Callaghan, 2004).

Three stakeholder groups can be readily identified as having the ‘power’ to challenge these and other influences that militate against the provision of RSE – both formally and informally – to children and adults with intellectual disability.

First, family carers, especially older parents, tend to hold more conservative attitudes around sexual expression outside marriage (Cuskelly and Bryde, 2004). In countries such as Northern Ireland where higher proportions live with family carers well into their adult years (Barron et al., 2006), it is crucial to have an understanding of their perspective and for educational, health and social care services to build alliances with them. It is well accepted that parents have a significant role to play in RSE for children but the extent of parental involvement with their adult son or daughter who has a disability is largely unknown.

A second influential group are direct care staff working in day centres and supported accommodation for adult persons. Past research has identified the variations in attitudes that arise from their work settings, personal values and access to training (Grieve et al., 2008). Although there is often no formal requirement for these staff to provide RSE, they are well placed to respond to the needs of the people they support on an impromptu if not formal basis.

Thirdly, a range of clinical and professional staff in health and social services is deployed to assess and respond to the particular needs of individuals referred to them, for example, for inappropriate sexual behaviours. In planning individual treatment and intervention programmes, they aim to work in partnerships with family and/or direct care staff (Lambrick and Glaser, 2004). These professionals may have limited time to engage in preventive work but their skills and expertise would be a valuable addition to developing RSE programmes and supporting other personnel and family carers in their use.

Past research and initiatives to provide RSE for persons with intellectual disabilities have tended to focus separately on each of these three target groups. To date, little research has been undertaken that examines their perceptions on the provision of RSE within the same cultural context and at the same point in time. It seems self-evident that a partnership approach embracing all three groups would be more effective than initiatives taken by solely one group. Moreover, greater emphasis needs to be placed on identifying the extent of any consensus that exists across the groups as well as documenting significant differences among them if a common approach is to be fostered.

Hence the main aim of the study was to examine the attitudes in Northern Ireland of family carers, direct care staff and trained professionals (such as social workers and nurses) to the provision of RSE for teenagers and adults with intellectual disabilities. A further aim was to identify the areas of consensus among their perspectives so that recommendations could be derived for improving policy and practice so that people with intellectual disabilities have greater access to RSE.

Method

A qualitative mixed methods research design was adopted involving group and/or one-to-one interviews. The group interviews helped to identify the main themes that could be further explored in the individual interviews. A common set of trigger questions and probes was used so that respondents' experiences and opinions could be triangulated across the three target groups as well as adding breadth and depth to this complex area (Polit and Tatano-Beck, 2010).

In any qualitative research, it is important to acknowledge the researcher's perspective in the research process (Parahoo, 2006). Throughout the study, the lead researcher (AL) ensured that objectivity and impartiality were maintained at all stages of the project. For example, during interviewing, the trigger questions were kept open and broad; during data analysis, themes were cross-checked by a second researcher, with the two reaching a consensus; and the triangulation of methods and data sources allowed for cross-validation, verifying emerging key themes. The final themes were then confirmed by the relevant key stakeholders. These safeguards helped to assist the project researcher in guarding against any bias.

Recruitment of samples

A steering group was recruited for the project to assist with access to potential participants. It consisted of service professionals, frontline staff, a parent and two people with intellectual disabilities. Through their contacts and 'snowballing recruitment' the participants who took part were as follows.

Family carers. Initially two focus groups were held with 26 self-selected carers of teenagers and young adults from across Northern Ireland recruited through voluntary organizations. Following on from this, a further 19 interviews were conducted with 22 carers; the majority of these were mothers, followed by fathers, sisters, sisters-in-law and brothers of people with intellectual disabilities. They had volunteered to be interviewed after receiving an information sheet about the project from a range of services across Northern Ireland. These interviews provided more detailed insights into parental thinking around this topic and interviewing continued until data saturation had been reached.

Professionals. It proved difficult to arrange suitable meeting times for groups of professionals. Hence individual interviews were conducted with 24 professionals (15 female and nine male) from various disciplines working in the field of intellectual disabilities; mainly learning disability nurses ($N = 8$) and social workers ($N = 5$) but including also educationalists, social care managers and other healthcare professionals such as a psychiatrist, a psychologist and an occupational therapist. They were invited on the basis of their interest and expertise in the area of sexual health promotion and education. Once again data saturation was reached after 16 interviews, although as a further check staff from all the disciplines listed above were recruited.

Frontline staff. Five focus groups were held with 24 frontline staff (23 female and one male) recruited from social care day centres and supported accommodation services across Northern Ireland. It was evident that data saturation had been attained by the fifth group.

In total nearly 100 stakeholders were involved in the study. Further details of the samples and methodologies are available from the authors. The majority of participants were self-selected, and those who responded may have been inclined to be more open, accepting and supportive of the relationships and sexuality of people with intellectual disabilities and arguably more familiar with the challenges facing people with intellectual disabilities around RSE and how the barriers might be overcome.

Data collection

Ethical considerations. Ethical approval was granted by the Research Ethics Committee at the University of Ulster. All participants received an information leaflet that outlined the purpose of the study, explained the importance of undertaking this type of research, and provided reassurances to allay fears and misconceptions.

Developing trust and rapport with participants was deemed critical in alleviating any concerns or anxieties they might have had and in making participants more comfortable during the group and individual interviews. All participants had the opportunity to have any questions answered, were assured that all information given would be kept confidential, and were asked to sign a consent form. Participants generally appeared at ease during the interviews and few showed signs of discomfort.

Group interviews. The group interviews with frontline staff and family carers ranged in size from four to 19 participants. These were co-facilitated by a researcher and a research assistant. The groups for staff were mainly held in service settings and those for parents were in local settings such as community centres. With staff, a series of vignettes depicting queries from people with intellectual disability about sexual issues were used to trigger a focused discussion around RSE in their workplace; with parents, a set of trigger questions and issues was worked through in line with the study aims. The groups lasted between 60 and 90 minutes and detailed notes were taken throughout.

Semi-structured Interviews. One-to-one, in-depth interviews were conducted with professionals and family carers. Interviews generally took place in the professional's workplace and in the carer's home. As with the group interviews, the focus was on informants' views and experiences in relation to RSE for people with intellectual disabilities, the availability of relevant information and resources, and the support required to implement RSE. All interviews lasted between 30 and 90 minutes; they were audio-recorded and transcribed verbatim.

Data analysis

The information gathered from the group and individual interviews was analysed using thematic content analysis (Burnard, 1991). The themes were cross-checked by two researchers during data analysis and a consensus was reached. The triangulation of methods and informant groups also allowed for cross-validation of emerging key themes. It was evident too that data saturation had been achieved with all three informant groups as no new themes emerged in later focus groups or interviews (Parahoo, 2006).

Conclusions drawn from the findings were confirmed with the steering group for the project and at a later dissemination workshop held with representatives from all key stakeholder groups.

The findings

Two main themes were evident from the data gathered across all three groups. Firstly, there was consensus on the need for RSE to be provided, with strong arguments being presented in support of it. Secondly, respondents nonetheless were cognizant of the barriers that inhibited its provision.

Is RSE needed?

Nearly all family carers wanted the person in their care to receive age-appropriate RSE. The reasons were further elaborated in the interviews. For example:

> They're just like the rest of us! They have a body but they have to get to know and learn about it; learn about how to use it properly and protect it. (mother and father of a 18-year-old woman)
>
> It is essential that accurate age-appropriate information is shared with young people with learning disabilities. We would encourage debate and sex education both in school and at home – ensuring information is consistent and accurate. (mother of a 29-year-old woman)

Family carers were concerned that if their sons and daughters did not receive the appropriate education, they could be faced with a lot of confusion in their lives:

> My son is 14 and he is going through body changes and he doesn't know what is happening ... he started to get hair under his arm and he is trying to pull them out ... I'm concerned. (mother of a 14-year-old man)
>
> She's very confused at the minute and I think a lot of it has to do with the influence of television because she watches all the soaps. She is aware of teenage pregnancies, she's aware of homosexuality but I don't know that she fully understands what they really mean. (mother and father of a 19-year-old woman)

Likewise most frontline staff were in agreement that RSE is important for people with intellectual disabilities:

> With the community opportunities going up, I think the risks go up and more sex education is needed. (support worker)
>
> It doesn't appear fair that staff can have sexual relationships but the other adults with whom they work [the clients] must be discouraged from doing so. (day centre staff)

All the professionals interviewed were convinced that RSE was needed:

> I think that a lot of the problems today – whether it is challenging behaviour or mental health problems – stems from a holistic view *not* being taken of the client, that their emotional health or their sexual health maybe isn't being addressed. (clinician)

Professionals noted it was important that people understand their emotions:

> It's about emotional education too ... I've seen sometimes adults with learning disability not being taught about love or affection, or jealousy, so that whole emotional vocabulary is sometimes even lacking. (clinician)

Parents and frontline staff mentioned other topics for inclusion in RSE: namely, appropriate behaviour in public, masturbation, sexually transmitted infections, pregnancy and contraception.

The views from the three groups, coupled with those expressed by people with intellectual disabilities reported earlier and in previous studies, suggest there is strong backing for RSE for persons with intellectual disability, not just in schools but also in their adult years.

Is RSE happening?

Despite the support for RSE, respondents confirmed that in 'reality' little proactive RSE was being carried out, especially for adult persons. Service staff admitted that whenever it was provided, it was usually in response to incidents that had arisen:

> There's very little going on, any work that is going on is taken on by certain professionals who deem themselves that there is a need. Very often it's in response to some incident rather than any sort of planned educational programme ... so it tends to be reactive. (service-based professional)

Frontline staff felt governed by the rules and regulations of their place of work which often did not support them to work effectively on issues around sexuality and relationships:

> I'm sitting here and I feel like a complete hypocrite, because there is so much that I would love to be able to do but my hands are tied. If they [the clients] came to me and asked me for help I couldn't do it because my job and my neck would be on the line. (residential staff)

Provision in schools for older teenagers appeared to be inconsistent. Some were delivering excellent programmes but certain topics tended to be omitted such as sexual intercourse, contraception and sexually transmitted infections. Others focused solely on school leavers in order to prepare them for living in the community (Simpson et al., 2006). One mother commented:

> There is some sexual related work through school but they were just doing personal hygiene, personal skills, you know that sort of thing. (mother of a 16-year-old man)

Carers too seemed reluctant to broach RSE within the home. Although a majority of carers stated that they had discussed sexual health with their relative, only a few reported doing this frequently. They found it difficult to approach the subject or found themselves uncomfortable discussing the topic:

> I would find it very hard to talk about sexual intercourse or masturbation to him because I'm too close to him and he would be embarrassed and I would be embarrassed. (mother of a 19-year-old man)

> I would have no fears to talk to him, you know, and he would listen to me, but I just didn't know how to approach it. (sister of a 47-year-old man)

In summary, there is contradiction between the current lack of RSE provision and the strong advocacy for its provision by family carers, frontline staff and professionals as evident in these findings. The reasons for this inconsistency were further explored in the data analysis and are summarized in the next section.

The barriers to RSE

Four main barriers were identified across the three informant groups:

1. protection versus personal development
2. lack of training
3. scarcity of educational resources
4. cultural prohibitions.

These are dealt with in turn.

Protection versus personal development. Family carers spoke of the dilemma they faced around the vulnerability of their relatives:

> It's very easy to sit and say, I would love her to have a relationship and get married and in an ideal world that would be what her future would be, but at the same time, I think I would be terrified for her. (mother and father of a 19-year-old woman)
>
> Some parents are very loath to let go, and believe me, the hard thing is to let go, that's the very hard thing. The easiest thing is to keep them at home and protect them and make sure they are well looked after. (mother of a 19-year-old man)

The 'protection versus personal development' struggle apparent in these data is reflected in other research that suggests that some family carers want the person in their care to have the same rights as everyone else but that they are concerned for their safety (Garbutt, 2008). But this attitude is not exclusive to carers.

Professionals suggested that whilst it was important to view people with intellectual disabilities holistically and afford them their human rights and dignity, it was also essential to respond appropriately to their cognitive level and equip them with the knowledge to protect themselves. However they felt that given their professional responsibilities, protection is inevitably the priority:

> It was probably protection, I'll be honest, you know [the RSE] was limited and it covered their backside and it covered my backside as a practitioner and that, you did [what's] necessary to protect either the client or the client's partner or whatever the circumstances you know, rather than their development. (clinician)

Professionals used the attitudes of carers to justify this 'protection' focus, suggesting that some wanted the person in their care to be 'labelled' vulnerable regardless of whether or not this is applicable. They felt that the intention of carers was to restrict the activities of the person in their care and to dismiss or ignore his/her sexual needs. However, some professionals did acknowledge that whereas protection should be a priority for clients of all cognitive levels, the promotion of independence and autonomy should be a priority for those with higher ability.

Frontline staff working in day centres or supported accommodation reported feeling under pressure from managers and family carers to supervise and limit the sexual expression of their clients. Although they appreciate the lack of privacy and disrespect this entails, given their 'low status' in their services, they felt powerless to do anything about it:

> I know I would be very much for letting people with a learning disability experience the things that I would experience and have access to the things that I would have in life, but because of where I work, there are so many rules and regulations, I can't allow that to happen. (frontline staff focus group 2)

Linked to the protection versus personal development struggle was the delivery of reactive as opposed to proactive RSE initiatives. The majority of professionals described their work as mainly, if not entirely, reactive in nature and often in response to an incident such as inappropriate behaviour in a public place or where it was apparent that two people with intellectual disabilities were developing a relationship.

Lack of training. The second major barrier to emerge from the study was the lack of training opportunities for frontline staff on policy and practice in relation to sexuality, and professionals too requested further training on relevant legislation, parenting assessments and resource development.

Many frontline staff working in day centres or supported accommodation are on low pay and have no formal vocational qualifications. Although most agreed that RSE was important for people with intellectual disabilities and many spoke of a willingness to contribute to RSE programmes, only a minority had attended any form of training opportunities and knew of the guidelines in their service relating to sexuality. Most service staff felt unsupported by senior staff when dealing with sexuality and relationship issues with clients.

Professional staff reiterated the need for training but advocated that it should be supported by staff supervision procedures and organizational policies. In some cases no specific training had been received, whilst others had received training 10 years previously which was therefore outdated. This left professionals feeling vulnerable, ill-equipped and discontented:

> The in-depth training we were promised has never appeared. I believe we are very vulnerable as field work practitioners and we are out there and families are coming to us and schools are ringing us and saying, 'This is happening, what do we do?' (social worker)

Teachers also identified the need for training, and some stated that although they taught RSE they had never received any training on the subject. Several devolved responsibility to external agencies – clinical psychologists, nurses and other healthcare professionals – as they felt they are better equipped and more knowledgeable. However this limited the involvement of such personnel to 'one-off' visits.

Additional factors identified as affecting training provision were difficulties in releasing staff and lack of funding. It was also suggested that the experiential nature of training in this area of work often left staff with unresolved personal issues.

Carers also spoke of how ill-prepared they felt to act as educators for their relatives:

> I would like to have a wee bit of insight into what way that maybe I could deal with it, in what way I could go about talking to N and maybe try to get him to understand. But at the minute I just wouldn't know what way to approach it, you know what I mean? (mother of an 18-year-old man)

Others spoke of the value of learning from other parents' experiences:

> I have been very fortunate in that there's a group of parents that I have over the last lot of months been in a lot of contact with because of the transition [from school] and I'm not the only one feeling a bit helpless. (mother of a 19-year-old man)

In sum, all three informant groups felt ill-prepared to undertake RSE, perhaps because of the cognitive and communication limitations of persons with intellectual disabilities allied with the embarrassment often experienced when dealing with sensitive issues. A variety of training opportunities and formats is likely to be required.

Scarcity of educational resources. The third recurring barrier across all the groups was a perceived scarcity of educational resources. One mother summed up the problem thus:

> The resources that you would get for younger children aren't detailed enough ... you know they might get stuff that's aimed at primary school children, but it's not really what they're looking for, you want it to be real for them but at their level. (mother of a 14-year-old girl)

But a more common comment from carers was their lack of knowledge about any resources:

> It's still a very taboo subject and it's a problem getting information, so I think if there was a core centre where parents could gain that information. (legal guardian for 40-year-old man)

Family carers felt that suitable RSE resources and materials would help them to discuss these issues with their relatives:

> I would like to have something that maybe I could maybe read, to give me a wee bit of insight into what way maybe I could deal with it, what way I could go about talking to N and maybe try to get him to understand, but at the minute I just wouldn't know what way to approach it. (mother of an 18-year-old man)

Teachers also report a lack of suitable RSE resources and the lack of funding available to invest in them if they did exist. Many relied on materials they developed themselves:

> It would be lovely to have more resources that you could put your hand on and at the moment I'm building up resources and making things and it's slow, slow progress. (teacher)

Frontline staff and professionals commented:

> There is so little available and an awful lot of training material is really not appropriate; it's way above a lot of people's heads. (frontline staff focus group 3)

> The lack of appropriate information is the biggest barrier, level appropriate too ... it's no use giving them a leaflet, its needs to be something they can understand. If it's done in pictorial form, it's understandable. (clinician)

Ironically there are excellent resources available for conveying sexual information to people with intellectual disabilities, but clearly they were not generally known or made use of (Grieve et al., 2006). This reinforces the need for greater access to information and training, and for publicizing more widely the availability of both.

Cultural prohibitions. A fourth barrier to emerge across all three groups was cultural prohibitions stemming from religious beliefs. Northern Ireland society tends to be conservative with a high level of religious adherence. Political and community leaders along with family carers and service personnel may adopt defined positions with regard to what is acceptable sexual behaviour and even more so with regard to people with intellectual disabilities (Ryan and McConkey, 2000):

> I don't think the whole community has totally accepted learning disabilities ... that recognition that they are very different and they are not one of us and they wouldn't have sexual feelings and how would Johnny know about erections and penises, sure he wouldn't know that. (service-based professional)

Several professionals reported that religious beliefs were a major reason for parents' negativity to RSE because of their attitudes to methods of contraception and some forms of sexual behaviour:

> When we have included things like masturbation, parents have said masturbation is sinful! And it's against the Lord! (teacher)

As one teacher concluded:

> I think Northern Ireland is not a very open society and a lot of the ordinary schools don't do very much good sexual health education either, so I think society's attitudes are probably the biggest barrier to expectations that sexuality is a part of life for people with learning disability. (teacher)

The family carers who participated in the study were also aware that not all parents thought as they did:

> If you go and say to parents – we're having a wee meeting about sex – they're not going to go to it 'cause they're going to be embarrassed. I think the only way we're going to overcome that is to start talking about it. (mother of a 14-year-old girl)

One parent astutely observed:

> Services are antiquated in terms of treating them as adults ... perhaps because they take their cue from the parents' attitudes. (mother of a 20-year-old woman)

Professionals seemed to concur. Often they linked family negativity to RSE with the inability of carers to perceive the person in their care as an adult and the assumption that the intellectual disability precludes sexual awareness and desire. Nonetheless a recurrent observation was that younger carers were generally more positive than older carers:

> The younger parents of today have come on leaps and bounds and are well aware that their young son or daughter is and can be sexually active and have the same feelings as they themselves have. (service-based professional)

Finally, the way forward was in terms of partnerships, and this was best expressed by the family carers:

> I think it's everybody's duty, I suppose, it's a social problem and a community problem, I think everybody has responsibility for sexual education. (mother of a 14-year-old girl)

Discussion

In this study we have brought together the perceptions and attitudes of three significant groups of stakeholders. Although they were self-selected samples from one region of the UK, nonetheless the numbers involved and the steps taken to ensure replicability and confirmability suggest that the main themes identified in the data are robust and may have applicability to other countries.

Compared to research undertaken in the 1990s, there appears to be a strong consensus across all three groups on the need for RSE. This is perhaps reflective of a greater openness in society around sexual matters and more specifically a better appreciation of the changed aspirations and lifestyles of people with intellectual disabilities than has occurred in recent years.

Significantly, all three informant groups identified similar barriers to those previously identified which created a major dilemma for them. Although convinced of the need for RSE for people with intellectual disabilities, the obstacles they perceived effectively stymied any initiatives they might wish to take in this area. Hence the way forward is to reduce the real or imagined barriers that persist among these stakeholder groups. Reliance solely on the production of policy and practice guidance is unlikely to be sufficient in doing this. Implicit in the analysis of informants' responses are clues as to how this might be done and implications are noted for future research studies that could further inform the removal of barriers. Four interrelated activity strands are proposed, and although they are listed sequentially a start could be made with any one of them.

The provision of information

Frontline staff and professionals as well as family carers repeatedly mentioned a scarcity of resources, but there are excellent resources available for conveying sexual information to people with intellectual disabilities. Moreover, as an outcome of this research project, the Family Planning Association successfully sought funding to produce an interactive CD-ROM on sex, sexuality and relationships for people with intellectual disabilities (FPA, 2008). These resources need to be publicized and research undertaken into how this is best done to promote their usage. For example, an accessible local information leaflet or website for people with intellectual disabilities and their family carers could be prepared, which lists sources of information and support on sexuality and relationships.

As happens within some schools, a designated member of staff within local health and social services could be given responsibility for identifying suitable educational resources, accessing local and regional training opportunities for staff and family carers, and when appropriate enlisting the help of outside personnel to assist with the delivery of RSE within their service. To date, there have been few studies into the impact that changes in staff roles and responsibilities can have on implementation of new practices in RSE.

Training for staff and families

A major issue for frontline staff and professionals was the lack of available training on sexuality and relationships. Some were particularly concerned that even where services have policies and guidelines in place, there was inadequate training to enable them to ensure that these are put into practice. An additional concern for many was the absence of support for them when dealing with sexuality and relationships issues with clients. The development of a tiered training strategy seems appropriate, with induction and awareness raising being available to all staff followed by more in-depth training on specific issues. Ongoing supervision and support from line managers should form part of a training strategy.

In all the data gathering there was a striking lack of direct engagement of family carers and service staff around these issues. Hence an integral part of any training should be partnership working of staff with family carers. This may need to be done on a one-to-one basis, as parents may be reluctant to attend formal training sessions. Additionally peer education has been found to be an effective method of engaging young people to address sexual and reproductive health needs (Price and Knibbs, 2009). Similarly, through the use of peer trainers, this method could be equally effective with family carers. Parents and other relatives might be trained to co-tutor groups around topics of particular concern to families. This might both encourage parental attendance and facilitate attitude change and confidence building among families. The peer educators could also contribute to the training of staff as a further means of developing their skills in relating to parents. Again further research would help to identify the most effective ways of engaging parents in RSE.

Risk management

The vulnerability of people with intellectual disabilities to abuse was a primary concern of carers and many professionals, and paradoxically was cited as a reason for not providing RSE. However, reliance on protective strategies may not prove sufficient and greater attention must be paid to enabling people with intellectual disabilities to protect themselves, either from abuse or from having accusations of abuse levelled against them. At a minimum this requires them to appreciate the difference between appropriate and inappropriate sexual behaviour and to have the vocabulary to describe unwanted sexual encounters. Denying people such opportunities arguably increases their vulnerability. It is therefore recommended that all RSE initiatives in, for example, schools and day centres include information and education on appropriate and inappropriate behaviours, and the promotion of self-protection. This rationale for RSE also needs to be advanced among family carers.

But as the *Valuing People Now* review noted, services continue to get:

> The balance wrong between protecting vulnerable people and helping people have a life: positive risk taking should be a part of everyone's life, including those with more complex needs. (Department of Health 2009, p. 93)

However, the guidance on supported decision-making issued by the Department of Health (2007) contains few examples of how risks can be creatively managed. Rather the onus is on supporters and the people they support to negotiate the risk reduction strategies best suited to each individual. This area is ripe for further research and development.

Empowering people with intellectual disability

A fourth barrier is one that is included mainly because of its omission in the data obtained. Most respondents appeared to presume that they would be the instigators of RSE rather than providing it in response to requests from a person with an intellectual disability. Unlike non-disabled young people, persons with intellectual disabilities do not have the same ready access to all the different sources of information and, even if they do, they may not be able to understand the contents. Hence they remain dependent on others to identify and respond to their needs. An alternative would be to empower the person to request the support they may require. For example, advocacy groups have a particular role to play in the provision of training courses for their members. These might take the form of separate courses for women and for men and deal with specific issues of concern to the participants. There is potential too for peer tutors to be recruited and trained in facilitating the groups, as noted earlier. These tutors could also be usefully deployed in staff training courses.

At an individual level, when family carers request, or service professionals undertake, any form of person-centred review – e.g. in transition planning, after health checks, or in day activity programmes – the practitioner (for example, the keyworker) should raise the issue of sexuality and sexual health issues both with the person with the intellectual disability and with their family carer. The resulting person-centred plans should document the actions to be taken around the identified issues (or reasons why no action was taken). Moreover a commitment to the provision of RSE needs to come not only from schools but also from further and higher education, and other training agencies such as those preparing people for employment. Providers of supported accommodation might also wish to facilitate access for their tenants.

In conclusion, small practical steps taken by the various stakeholders seems the best way not only of reaching a consensus around RSE for persons with intellectual disabilities but of making sure it happens in practice. Likewise future research and evaluation should be directed at understanding better the implementation of RSE and its adaptation to local circumstances and need. The outcome of both approaches hopefully will be that persons with intellectual disabilities, unlike their peers in previous generations, enjoy positive relationships, and experience good sexual health and wellbeing. Indeed this is the gold standard against which effective RSE can be judged.

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Note

1. In the United Kingdom, the term 'learning disability' is used for people referred to internationally as having an intellectual disability. In this article we have retained the term 'learning disability' when reference is made to service provision and policy statements and in quotations from research informants.

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