

# Promoting Positive Relationships and Sexual Health for Adults with Learning Disabilities within a Community Setting

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Despite the growing evidence that healthy sexual and romantic relationships enhance the overall wellbeing of people with learning disabilities (PWLD), this has often been overlooked or discouraged. This, in part, can be attributed to the difficulties PWLD face in understanding the abstract concepts associated with sexuality and healthy relationships. Societal attitudes and the social construction of the term “learning disability” have also typically placed PWLD at a social disadvantage, thus restricting their opportunities for sexual experiences and learning. A group programme for PWLD was developed to promote positive relationships and sexual health within the community. The course ran over six weekly sessions and addressed different topics relating to sexual health, interpersonal relationships and societal expectations of behaviour. A secondary training workshop was also developed for staff members supporting those with a learning disability. Qualitative and quantitative feedback highlights an increased understanding of sexual relationships amongst participants. Reflections on the implications and limitations of this study are discussed.

An individual with a learning disability, by definition, has significant impairment of intellectual functioning, has significant impairment of adaptive behaviour (social functioning), and both impairments will have arisen before adulthood (Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology, 2015). Despite these differences, forming relationships with others is just as important for people with learning disabilities (PWLD) as it is within the general population (Department of Health, 2009). Having the opportunity to form different types of relationships including those of a romantic nature is vital for PWLD to maintain a good quality of life, aid social inclusion and help protect against mental health issues (Emerson & Hatton, 2007). Despite its importance, this is an area that has historically been overlooked, ignored and even actively discouraged within society (Lindsay, 2002; Valios, 2002; Servais, 2006).

Services have come a long way in supporting PWLD to be included in society and to make informed choices about their life however, relationships and sexual health remains one of the most neglected areas of support (Emerson & Baines 2010). When compared with the general population, PWLD show lower levels of knowledge about almost all aspects of sex and are significantly more vulnerable to abuse (Murphy & O’Callaghan, 2004; McCabe, 1999). There is also evidence of a higher prevalence of sexually-transmitted

diseases amongst men with a learning disability (Van Schroyen Lantman De Valk et al., 2000; Department of Health, 2013).

Whilst the need to promote sexual health for the learning disability population is evident, providing this support is not without its own challenges. Sexuality is an abstract concept which comprises a complex interplay of biological and psychosocial issues (Carr, 1995). In addition, society's conventions and expectations with regards to sexuality are both culturally and context specific and can change over time, making it particularly challenging for PWLD to understand. Littler (1998) also highlighted that PWLD have less access to learn about sex and relationships through common informal channels such as peer relationships. McCabe (1999) reported that PWLD learn most information from the media which limits the opportunities to check the information is accurate or to discuss issues. Fewer opportunities to understand about sex and relationships, combined with difficulties comprehending information, are likely to lead to confusion.

In addition to the difficulties cognitive impairments can place on the understanding of sexual health, compared to the general population, PWLD are also placed at a social disadvantage. The amount of social opportunities to engage and meet new people can be limited and some are required to move across locations to have their housing needs met (Department of Health, 2009). A consequence of this means the chances to not only form new relationships but also to sustain long term relationships that are meaningful to the service user are limited (Department of Health, 2009). The impact of this is likely to lead to difficulties in learning the necessary social skills and knowledge about different types of relationships that are required to not only allow an individual to explore their own sexuality but also the means of maintaining a healthy sexual relationship with others (NHS Highland, 2007; Fraser, 2008).

The barriers for promoting sexual health needs for PWLD should not be simplified to an individual level. It is important to recognise societal attitudes towards sex and PWLD as well as the attitudes and beliefs of those supporting them. The social construction of the term 'learning disability' has often meant individuals have either been perceived as asexual, a vulnerable adult or a sexual predator (Giulio, 2003; Morris, 2001; Mencap, 2016). Given the underlying context, sexualised behaviour has been something those supporting the individual have feared in causing harm towards others, or it has been viewed as a behaviour the individual needs protecting from (Brown & Stein, 1997; Craft, 2004). One line of thought services are often faced with by those supporting service users is whether increasing knowledge about sex and relationships will impact on increasing inappropriate sexualised behaviour (NHS East of England, 2010). However, as Carr (1995) explains:

*"people with a learning disability must be prepared for the adult world. Their vulnerability means that they need more than just a sex education programme. Coping with possible sexual exploitation is about knowing your rights, having the chance to experience relationships and knowing how to react and behave within them. Ignorance is not bliss, it is dangerous."* (p. 1136).

Nevertheless, it is important to recognise the reality of promoting good sexual health can pose a real dilemma for staff and families who can struggle to get the balance between

supporting the development of sexual/romantic relationships against issues relating to capacity to consent and protection from harm (NHS East of England, 2010). The lack of clear guidance and support on sexual health can disempower staff and families, often leading to confusion and a perception they lack the ability to support the PWLD, perpetuating the cycle of sexual health needs being unaddressed (NHS East of England, 2010).

Unsurprisingly, research has highlighted the importance of providing relevant, accessible and practical information. This should not only help address the difficulties family and staff face in supporting service users but also aid individuals to make informed decisions about their own sexual health which promotes their safety (Department of Health, 2009, 2013; Garbutt, 2008). Part of making information accessible is to provide information to service users that is meaningful and person-centred (Mencap, 2000). Due to the social and cognitive difficulties associated with having a learning disability, it is unlikely sex education provided to the general population will help inform future thinking and behaviour for those with learning disabilities. More than likely, the focus will need to be on family/staff to reinforce previously learnt information throughout adulthood to enable service users to navigate complex social and relationship scenarios and for service users to be able to access support from specialist learning disability services around specific concerns with sex and relationships (NHS Highland 2007). Given this, commissioners of services have urged services to focus on providing “guidance for staff and families” (NHS EOE, 2010) and to develop “accessible information- about sexuality, abuse and consent and practical information about contraception and safer sex” (DOH 2013).

## **RESEARCH INTO PRACTICE**

This article describes and reflects on a new group programme designed to promote sexual health and social skills in PWLD within a community setting, with the additional aim of covering societal expectations of behaviour. Rossiter et al (2016) highlight some of the advantages of group interventions which draw on a range of psychological models. These include an increase in participant’s skills in particular areas and are in addition to the practical benefits of providing group interventions, such as cost efficiency and the opportunity for participants to develop new relationships with peers (Ward et al 2012). A psychoeducation model was considered to be most appropriate in this instance in order to provide information in an accessible and meaningful way and to give participants the opportunity to practice new skills such as problem solving socially complex scenarios in a role play scenario. The planned intervention consisted of an assessment, six weekly group sessions for service users and their carers, a two-hour pilot workshop for staff supporting the service users and an outcome evaluation, described in more detail below.

## **ELIGIBILITY FOR THE GROUP**

The following eligibility criteria were used when recruiting for the group:

- Diagnosis of learning disability
- Males (the majority of referrals were for males and it was felt a single sex group was more appropriate in this instance)

- Referred to Psychology and on the waiting list for support with understanding of sex, relationships and societal norms
- Ability to concentrate during the session and work in a group setting.
- Settled in mood and not posing a significant risk of harm to self and/or others.
- Expressed interest in learning about sex, relationships and societal norms

## **ASSESSMENT**

Prior to the group, all service users were accompanied by a family member or a carer to meet with a member of the clinical psychology team to complete an assessment of their socio-sexual understanding and current concerns. A total of thirteen referrals across two group cohorts were received requesting support for male service users with their understanding of sex and relationships. These referrals were made by family members, carers and various health and social care professionals. As part of routine clinical practice, initial information about each referral was collected from the referrer and was discussed within the psychology team as to what intervention would be most appropriate. Those individuals who did not meet the inclusion criteria of the group were placed on the waiting list for individual therapy. Service users were provided with an information leaflet which included information about the content of the group and confidentiality. Service users were informed that information from sessions would be written in their medical records and may be written up as part of a research paper. Service users were reminded it was their choice as to whether they attended the group and a consent form was provided. All participants provided consent to this article being written.

## **PARTICIPANTS**

Across the two group cohorts, 13 referrals were eligible for the group (six service users were eligible for the first group cohort and seven service users were eligible for the second group cohort). In total four service users attended the first group and four service users attended the second group, resulting in an overall number of 8 service users across both groups. The distances required to travel to the group and service user support staff unavailability were the main reasons why the remaining 5 service users were unable to attend.

Service users were aged between 18 and 62 years and were diagnosed with a learning disability ranging from mild to moderate severity. The term mild to moderate learning disability refers to an impaired adaptive functioning and IQ ranging from 50 to 69. Most service users were supported to attend the group by a family carer or member of staff who knew them well. Two service users declined to be supported by a family member in the session although were supported with completing the homework from the group. Attendance in the group was a challenge with only four service users attending all sessions. Regular telephone contact was made with service-users and carers between sessions to explore the reasons for nonattendance and to establish whether they planned to continue attending the group. In addition, materials from missed sessions were sent out by post for service-users to complete with carers prior to the next session.

## **GROUP SESSIONS**

The group sessions were held every week over a six week period for 90 minutes. There was a 10-minute break after 45 minutes. The sessions took place at an easily accessible location within the community. The structure of the sessions was centred around a consistent framework which included: reintroducing the group rules, a recap of the previous session and introducing a new topic using group discussions, activities, handouts and video clips. Homework was set most sessions, building on the skills and knowledge learnt during each session and easy-read handouts were provided as a reminder of the session content.

The group sessions comprised of the following topics and content:

### **Session One**

Introduction to the group and different types of relationships:

- Introduction to the group, aim and structure. Group rules were introduced.
- Introduction to different relationship types: friends, family, romantic and professional relationships.
- Activity: service users were asked to write or draw their professional, personal and romantic relationships in their relationship circle worksheet.
- Homework: take pictures to add to the relationship circle worksheet.

### **Session Two**

Appropriate and inappropriate behaviours in relationships:

- Recap on different types of relationships and discuss homework.
- Discuss appropriate and inappropriate behaviours within different relationships (e.g. friends, family, romantic and professional).
- Discuss “relationship rules” using role play, video clips, social stories and picture cards. Relationship rules included: Personal space, touch in different relationship types, asking before touching someone and things that we should do in all relationships (e.g. be polite, respect others, look and listen to others when they are talking).
- Homework: complete worksheet with examples of what it is ok and not ok to do with different relationship types.

### **Session Three**

Sex education:

- Recap on appropriate and inappropriate behaviours in relationships and discuss homework.
- Identify different parts of the male and female body (using body map diagrams to label body parts).
- Explain sexual intercourse and different types of sexual contact using pictorial handouts.
- Discuss sexual contact rules.
- Activity: Watch two video clips of appropriate and inappropriate sexual contact, followed by a group discussion about whether the people in the videos are breaking the sexual contact rules.

- Homework: service users are given the Loving Each Other Safely (Bailey & Upton, 2011) picture book, illustrating how to stay healthy and safe in a romantic relationship.

#### **Session Four**

Safe sex:

- Recap on sex education and discuss homework.
- Group discussion on consequences of sexual contact, pregnancy and sexually transmitted infections using easy-read handouts.
- Discuss contraception and use pictures to explain how to put a condom on correctly.
- Activity: Condom cards – service users asked to put cards in the correct order to explain the process of using a condom.

#### **Session Five**

Societal rules and boundaries:

- Recap on safe sex.
- Explanation of societal rules when in the community, when in romantic relationships and when living in shared housing with other people, using easy-read pictorial handouts.
- Activity: Provide three scenarios (community, romantic relationships and shared housing) of someone breaking the rules and discuss what was wrong about this behaviour, how this made those involved feel and what should have been done instead.
- Activity: Service users asked to complete a worksheet in order think about what they should do if they do not understand the societal rules and do not know how to behave.

#### **Session Six**

Abuse and staying safe:

- Recap on societal rules and boundaries.
- Explain human rights and different types of abuse using easy-read handouts.
- Activity: read through different scenarios as a group. Service users asked to identify which scenarios are abusive and non-abusive and identify specific type of abuse if applicable.
- Activity: Service users asked to think about who they could ask help from if they were being abused, and developed their own “Keep Safe Card” with this information on.
- Quiz and outcome measures completed at the end.

A secondary pilot workshop was also developed for staff members supporting the service users and was held across one half day. This was attended by three female support workers from one staff team. The aims of this training workshop were to enhance staff member’s understanding of why it is important to discuss sexual health with service users, describe the potential barriers that prevent sexual health needs of people with learning disabilities being met, improve awareness of accessible resources that are available for staff teams and to provide practical information and tips to enable services to address client’s sexual health needs.

## OUTCOMES

Outcomes were assessed primarily through qualitative methods, including an idiosyncratic mid-point and end of group evaluation feedback form, asking what the group had discussed, what the participant enjoyed, what they did not enjoy and anything that could have been done differently. The NHS trust wide "Have Your Say" form was also completed at the end of the group by participants and carers. The participants reported enjoying the group, wanting to attend again because they felt they learnt a lot, "learning good manners and how to behave" and reporting day centre staff noticing they had "changed into a man" by behaving more appropriately around women. They also reported; learning to ask first to hold hands with someone, learning new things about sexuality, the group getting on well together, being able to talk about private things and learning through video clips. One service user fed back that he would have benefitted from bigger writing on handouts and the flipchart board, and that there could have been more people in the group.

In terms of carer's feedback, one carer reported that the person they cared for is now better informed, but they weren't sure that this had had an effect on his behaviour with his girlfriend. They also continued to have concerns about the service user's manual dexterity in practicing safe sex. Another carer reported that the service user had been discussing sex and relationships with staff and had looked through the BILD "Loving each other safely" book as well as his group booklet whilst at home. One carer enjoyed watching the way the group was presented and conducted but felt that the facilitators could have made more adaptations for one service user's visual impairment. Another carer felt some of the content was difficult for their service user to understand or embarrassing to talk about.

Alongside the qualitative feedback, the following quantitative measures were also used in order to build upon the subjective views of those attending the group:

An assessment of service users' knowledge was completed at the beginning and end of the group using the British Institute of Learning Disabilities (BILD) 'exploring sexual and social understanding' measure (Dodd et al., 2007). Post group service users demonstrated a greater understanding of sex, the potential consequences of having sex, where it's appropriate to have sex and who with, how to practice safe sex and knowledge of female body parts. Three service users were still uncertain about the legal age of consent for sex and one was uncertain about two female body parts and sexually transmitted diseases. One service user who only attended two sessions remained unsure about some male body parts and the potential consequences of sex. Furthermore, the psychology service Ridgeway Routine Outcome Measure (RROM) was used in order to record an overall rating of how the service user perceives their life to be at the moment (1= the worst things have been, 5=the best things have been). Due to the level of learning disability, service users were supported by their family/carers to complete the questionnaire as well as the carers views being sought where appropriate. All service users scored 5 out of 5 at the end of the group and all the carers attending the group scored 4 out of 5 for the service user they were supporting.

In terms of qualitative feedback from the subsequent workshop, staff who attended reported that they “agreed” or “strongly agreed” that facilitators appeared knowledgeable about the topic. Feedback was either neutral (neither agree nor disagree) or positive (agree or strongly agree) on the following aspects: training was pitched at the right level; the session was varied enough and the hand-outs were useful. Staff all “agreed” that they learnt something new from attending the training and that they would be able to use this new learning when they got back to work.

All staff commented that the secondary workshop was good as a taster session and was informative, but thought it would be better if it was more detailed and over a longer period of time. Staff reported that from attending training they would be more able to help with advice, ask questions if needed and be better listeners. Staff stated that they would monitor their progress in implementing the change by; discussing information/findings at handover with managers and other staff members, discussing overall learning from training and by putting new care plans into place.

## **DISCUSSION**

Despite the limitations of this being a small-scale intervention, the majority of feedback from both qualitative and formal outcome measures indicate that service users and those supporting them found the group and workshop to be a positive experience which has enhanced their understanding of relationships and sexual health within a safe environment. With so many potential areas to include in an intervention of this kind, it was beneficial to tailor the package to the particular needs of the service users.

An important aspect of the group was for service users to be supported by staff who knew them well. This enabled information to be delivered in a way that was meaningful, person-centred and accessible (e.g. key word signing, everyday language used by the service user). The emphasis on providing an environment that was predictable which had the same structure every week, allowed service users to explore topics to support their learning in a non-judgemental, open and honest format. The group also provided staff with the opportunity to start discussing issues related to sex and relationships and potential sexual needs of the service user they support. Providing service users with a booklet helped create a foundation from which staff supporting the service user could frame future discussions about their sexual health needs as well providing concrete accessible information the service user could refer back to, aiding their understanding of information.

Whilst it is crucial to address the positives that arose from the group, it is also important to note the challenges of delivering the group. One of the main difficulties that facilitators encountered was the lack of appropriate standardized measures to evaluate the effectiveness of the group. There appears to be a limited number of available resources that are robust to measure knowledge around sex, relationships and in particular societal expectations of behaviour. Due to this, the evaluation of the group relied heavily on qualitative feedback from carers/family and service users.

The sporadic attendance of some service users meant that they lacked the same awareness of the content compared to those who attended all the sessions, although the

information was sent to them in the post. This presented facilitators with a challenge to try and provide time to allow for a longer recap of the previous session in order to build upon service user's understanding in the current session, thus impacting on the time spent on new material. For this client group their cognitive and language difficulties means it is unlikely service users who missed more than one session would be able to benefit from understanding the content of the group and applying their learning to behaviour.

The use of social stories as examples of appropriate/inappropriate behaviour was difficult for some of the service users with a more severe learning disability. This may be due to the social stories used in the group being unfamiliar to them, with fictional characters and quite abstract concepts. However, as noted from the qualitative feedback, the use of more visual resources such as video clips, clips of real people interacting with each other and a sex education video may have supported service users understanding around these topics.

The severity of the service users cognitive and communication difficulties that attended the group meant that they required additional examples and information to be repeated and broken down into more manageable pieces. Due to this, some of the original content could not be covered during the group and service users may not have been provided with enough time to understand more complex or abstract concepts that were more difficult to understand. Given this, service users may benefit from the group running over eight sessions as well as providing a follow up meeting to see what information was retained and what was more difficult to understand. During this follow up it would be helpful to assess whether the group intervention had resulted in any direct behaviour change, linking to an improvement in the original reason for the referral.

Despite the considerations that will need to be taken into account if this group intervention were to be replicated in the future, it was felt that this programme began to address the difficulties PWLD, and those supporting them face around issues of sexuality and relationship boundaries within the community. It is also worth highlighting the need for future research and development in regards to the wider contextual factors that play a part in this area, for example societal attitudes towards sex and relationships within this population.

## **CONCLUSION**

Overall, we feel our current programme has been a helpful way for service users and staff to find out more information about sexual health and societal boundaries of relationships. Whilst the sample size of the group is too small for formal analysis of the outcome measures that were completed, we feel the group and workshop benefited service users and staff who attended, as well as addressing local authorities recommendations on supporting the sexual health needs for people with learning disabilities. It is hoped that pilot data from the workshop will support the implementation of a wider training event for support staff and families around relationships. When thinking about future work there is an ongoing need to build on this current study, with the aim to better support, promote and encourage safe sexual relationships for PWLD within today's society.

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