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Title: Health knowledge and the impact of social networks and engagement on young people with intellectual disabilities

Abstract

Background: Cognitive impairments are often assumed to underlie individuals' difficulties with understanding health issues. However, it was predicted that being part of a group who are more likely to be socially marginalised means they would have greater difficulty gaining understanding of sensitive topics related to sexuality than other public health messages, such as alcohol use.

Method: The health knowledge of 31 typically developing young people, 29 young people with mild intellectual disabilities (ID) and 23 participants with physical disabilities but no cognitive impairments, was compared.

Results: The largest group differences were related to more private and personal health issues, such as pregnancy/contraception. Both groups of young people with disabilities had less knowledge of pregnancy/contraception than their peers without disabilities. Thus, deficits in this sexual knowledge did not just appear to be the result of cognitive deficits.

Conclusions: The findings suggest that limited social networks and engagement may contribute to young people with intellectual disabilities' poorer knowledge of pregnancy and contraception. The results have implications for interventions.

Introduction

Tackling health inequalities faced by people with intellectual disabilities in early life has been recognised as a priority in the general population in the UK and internationally (The Marmot Review, 2010). Despite increasing evidence about the impact of broader social factors such as socio-economic disadvantage (Emerson & Hatton, 2007a,b,c), household composition, social capital, and disability-related discrimination (Emerson, 2012), the focus in practice often remains on how individual characteristics influence the health behaviours of people with intellectual disabilities. In particular, there has been a great deal of attention on the health knowledge of people with intellectual disabilities (Jahoda and Pownall, 2014).

Unsurprisingly, studies have documented low levels of health knowledge in people with intellectual disability across a number of health domains, including healthy eating (Golden & Hatcher, 1997; Illingworth, Moore & McGillivray, 2003; Jobling & Cuskelly, 2006; Rodgers, 1998), alcohol use (Jobling & Cuskelly, 2006) and sexuality (McCabe, 1999; Galea et al., 2004; Siebelink et al., 2006; McCarthy, 2009a, 2009b; Cheng & Udry, 2003; Isler et al, 2009). However, a focus on people with intellectual disabilities' cognitive impairments and lack of understanding may overshadow the impact of the wider social context. In particular, the role of social engagement in limiting access to key health messages has not been given proper consideration.

Not all health messages are difficult to access. Information about the risks of smoking or the importance of eating sufficient fresh fruit and vegetables, are in the public domain (Leung et al, 2009). These health matters are not just taught to young people in schools, they are also covered in public health campaigns in the media.

However, there are greater challenges when attempting to gain access to information about sexual matters. Sexuality is a more private and sensitive topic, often shrouded with taboos and subject to moral judgment (Gougeon, 2009). In her account of sex education for people with intellectual disabilities, Gougeon highlighted the importance of young people having the opportunity to exchange ideas and discuss sexual topics with peers. Otherwise, being a private topic, young people might be left alone to try and make sense of the confusing and often conflicting information they pick up from the media, school and other sources. People also learn about sexual matters through experiential learning, something that is more difficult to do when continuing to be under adult supervision, as many young people with intellectual disabilities are (Pownall and Jahoda, 2012).

To access proper information tailored to their needs, there has to be a recognition that young people with learning disabilities are achieving adulthood and have a right to be considered sexual beings and to have the necessary information to allow them to be sexually active. Gougeon (2009), highlights a refusal to acknowledge people with intellectual disabilities' adult status as one of the main reasons for ineffective sex education in schools that fails to meet these young people's needs and she advocates a more progressive stance. Moreover, longstanding and contrasting social stereotypes about the sexuality of people with intellectual disabilities may also contribute to the difficulties they have with accessing information from other professionals, like medical practitioners. At one extreme they have been viewed as devoid of adult sexual desires and vulnerable, and at the other as oversexed and dangerous, unable to control their sexual urges (Murphy, 2016).

It might be hoped that people with intellectual disabilities could use other sources of information about sex to compensate for the loss of these informal sources of support and limited school based sex education. Unfortunately, communication difficulties and reduced literacy skills make it difficult for these individuals to access other resources available to their peers without disabilities (Cheng and Udry, 2003; Blum et al., 1991; McCabe, 1999; Morrison, 2006). Nor do family seem to fill the educational gap, with recent research suggesting that young people with intellectual disabilities communicate less with their parents about sexual matters than their peers without disabilities (Isler, Beytut, Tas, & Conk, 2009; McCabe, 1999; Pownall et al, 2011; Pownall et al 2012).

To our knowledge, no study has examined the difference between health concerns discussed openly in the pubic domain and knowledge about more personal health matters. If the key barrier to health knowledge for individuals is solely about understanding, then one might expect cognitive ability to be the main predictor of knowledge for topics like pregnancy/ contraception, alongside other health issues such as the five-a-day message regarding the consumption of fruit and vegetables or the potential harm associated with alcohol abuse. However, if social engagement plays a part in the development of sexual understanding, then the extent of people's social networks and their opportunities to access sources of information, may be contributory factors to such understanding. Therefore, in a departure from previous research in this area, an attempt was made to explore the impact of both intellectual ability and the extent of social networks. To achieve this, we compared health knowledge across three groups of adolescents: those with (i) no disability, (ii) an intellectual disability and (iii) a physical disability but no cognitive impairment, in relation to their health knowledge and understanding of two ‘public’ health topics (healthy eating and alcohol use) and one more ‘private’ health topic (pregnancy/contraception). Having a second group of young people with physical disabilities who are also more likely to be socially marginalised but have no cognitive impairment, helped identify the particular contribution of social networks and engagement in determining the young people’s health knowledge.

Data was also collected about these young people’s social networks and sources of information about the health topics, to confirm whether or not there were differences in social engagement between those with and without disabilities.

Method

Participants

Eighty-three participants formed the three groups, of whom 31 had no known disability (ND), 29 had an intellectual disability (ID) and 23 had a physical disability (PD). The socio-demographic characteristics of the participants are shown in Table 1. Participants were aged between 16 and 21 years and recruited from further education colleges in a Scottish city. The colleges offered Supported Learning Courses for young people with intellectual disabilities, meaning that young people with and without intellectual disabilities could be recruited from these establishments. It was not possible to recruit all the sample of students with physical disabilities through further education colleges. Therefore, young people were also recruited from a specialist school catering for those with significant physical disabilities in the West of Scotland.

The school and colleges were mixed gender and had no religious affiliations. Sixteen years of age is the legal age of consent in Scotland.

Table 1 about here

The socio-demographic characteristics of the three groups of participants are shown in table 1. Every effort was made to ensure participants were similar in age, gender and social-economic status. To assess whether participants differed on any of the demographic variables, a series of Kruskal-Wallis and Mann–Whitney tests were performed. Intellectual ability was assessed using the Wechsler Abbreviated Scale of Intelligence (WASI-II). As expected, there were group differences ($\chi 2$ (2) = 58.134; p = 0.001), with pairwise comparisons showing the group with intellectual disabilities to have lower WASI-II-IQ scores than both the group without disabilities (U = 899.0, z = 6.686; p=0.001) and those with physical disabilities (U =667.0, z = 6.195; p=0.001).

Groups also differed by age ($\chi 2$ (2) = 28.586; p = 0.001). The physically disability group were younger than both the without disabilities (z = U = 625.0, 4.799; p=0.001) and those with intellectual disabilities (U = 625.0, 88.0, z -4.634; p=0.001). This was due to most of those with physical disabilities being recruited from schools, rather than colleges. The groups were similarly distributed across the neighbourhood deprivation categories. The majority of participants lived at home with their family, with the exception of two participants with intellectual disabilities who were living in supported accommodation and five of the group without disabilities who were living independently.

Measures

Demographic information. A brief demographic questionnaire was used to record information about participants' age, gender, and living situation. A deprivation category (DepCat) was derived from the Carstairs score (Carstairs & Morris, 1991), which indexes neighbourhood deprivation based on area of residence and was specifically developed for analysing Scottish health data. The Carstairs Index uses four indicators of deprivation (male unemployment, proportion of all persons in household where head of household is social class IV or V, overcrowding and car ownership) to create a composite score. This score is divided into seven separate deprivation categories (DEPCAT). DEPCATs range from 1 to 7 and the higher the score, the higher the level of deprivation.

Development of the Health Knowledge Questionnaire. A multiple-choice questionnaire with visual illustrations was developed by the research team to collect data about young people's health knowledge in two health topics in the public domain (healthy eating and alcohol use) and one more sensitive and private health topic (pregnancy/contraception). Whilst there are a number of existing health knowledge questionnaires and tools that have been developed for people with intellectual disabilities (Illingworth, Moore & McGillivray, 2003; Golden & Hatcher, 1997; Jobling and Cuskelly, 2006; McCusker, Clare et al., 1993; Wish, McCombs, and Edmondson, 1979; McCabe, 1999; Galea et al., 2004; Siebelink et al., 2006; Cheng and Udry, 2003), none of them were suitable to address the aims of the current study. Firstly, we required a single measure that was comprehensible and meaningful to young people with and without disabilities that minimised floor or ceiling effects. Secondly, we required a measure that would assess knowledge of health messages that are provided by the Scottish education system. Finally, we needed a questionnaire that would allow comparisons of knowledge across the different heath domains, including both public health messages and more private sexual topics.

The questionnaire content was informed by existing questionnaires referred to above, Scottish health education curricular guidelines (Health Education: 5-14 National Guidelines, Learning and Teaching Scotland; The Health Education for Living Project, HELP; Learning and Teaching Scotland, 1998), and health websites (www.healthscotland.com; www.healthyrespect.org.uk; www.cklearn.org.uk). This helped to ensure the content and terminology used within the questionnaire corresponded to that commonly used in health promotion messages for this age group.

Initial stages of questionnaire development involved discussing materials with young people with and without disabilities. This allowed us to check the usability and acceptability of the questions and helped determine the response alternatives to the multiple-choice questions. A multi-choice format was used because closed questions have several advantages, including ease of data collection and obtaining standardised information. More importantly, closed questions also make it easier for participants to respond to questions of a sensitive nature, for example regarding sexual health.

Once developed, the questionnaire was piloted with eight young people, four of whom had an intellectual disability, one a physical disability and three with no known disability. As a result, some questions were removed to shorten the questionnaire and questions that produced a high non-response rate (i.e. ‘don’t know’) were removed or reworded to reduce ambiguity and maximise clarity. Where participants requested further information, supplementary questions or probes were added. Visual stimuli were used to represent response options and to enhance the reliability of participants' answers (March, 1992; Sigelman and Budd, 1986; Heal and Sigelman, 1995).

Using high quality photographs and illustrations ensured that the questions conveyed similar meanings across the three groups of participants and helped to reduce memory load. Piloting highlighted that some photographs/illustrations failed to represent the concept in question and different photos or illustrations were used. For example, several participants failed to recognise a photograph of a rolled up male condom. However, using several photographs together, of the condom in a packet, rolled up and unrolled, increased recognition. Moreover, asking participants to 'post' their responses into a box (Turk and Burchell, 2003) helped to engage participants. Making the knowledge assessment an active task also helped to maintain motivation throughout the interview and reduced feelings of embarrassment or a lack of confidence when dealing with sensitive topics.

The final version of the questionnaire consisted of 24 multiple-choice questions. For each of the three health topics (healthy eating, alcohol, and pregnancy/ contraception) there were eight questions in a multiple-choice format. Three questions adhered to an agree/disagree/not sure format, for example "Always adding salt to your food is bad for you?"[agree], "Drinking alcohol is like taking a drug" [agree], and "You have to have sex more than once to become pregnant/get a girl pregnant? [disagree]. Five questions had three response alternatives to choose from, for example, "Which of these should you eat the most of…vegetables, cheese or meat? [vegetables], "Drinking two pints of beer would… Slow down your thinking / Help you think better

/ Be just the same (Slow down your thinking), “Taking the contraceptive pill if you are having sex can help stop you…getting AIDS, pregnant or both? [pregnant].

Each question was presented on a separate A4 page and response options for each question were attached by Velcro. Participants were required to ‘post’ their selected response into a box. At the beginning of the interview, participants were presented with several ‘practice’ questions (for example, choosing the food item from four possible response options), to ensure they understood what they were required to do and were provided with feedback and corrected if necessary. Questions were scored as either correct or incorrect, giving a maximum score of 8 for each section. As the aim was to examine inequalities in development of health knowledge, the three subscales were analysed separately. The interviewer read out the questionnaire and efforts were made to deliver the questions in a sensitive and understandable way, rephrasing when required. This meant being open and clear to help minimise the young people’s embarrassment and,giving them time to respond to questions. Where appropriate, more colloquial words were used (for example for alcoholic beverages, body parts, and methods of contraception).

The test - retest reliability of the scale was explored with two participants at a four week interval. The overall percentage agreement was 89.5%. For the individual scales, the percentage agreement was: 81.2% for the pregnancy/contraception scale, 87.5% for the healthy eating scale, and100% for the alcohol scale. Thus, the responses were relatively stable over time, with one/two items changing across time. Even then, all responses to the items where there was disagreement were incorrect at both time points and did not influence the participants’ overall score.

Sources of Information Questionnaire. For each of the health topics (healthy eating, alcohol use, and pregnancy/contraception) participants' sources of knowledge were assessed. Participants were presented with a list of five sources (family, school/college, friends, health professional, and media) and asked if they had obtained information from these sources. These sources were consistent with those described in previous literature (Packard & Neumark-Sztainer, 2001; Jahoda & Pownall, 2014). Visual stimuli were used to illustrate the predefined sources and probes were used to elicit information on each named source, in order to help ensure the veracity of the reports. Finally, participants were asked if they had obtained information about the health topic from any other source. A second rater listened to five randomly selected interviews, and there was 100% agreement about the sources participants reported accessing.

Social Network Questionnaire. A semi-structured questionnaire was used to explore participants' social networks. To start the interview, participants were presented with a visual illustration of a week (Monday – Sunday) and were asked what activities they did on each of the days and with whom. This allowed a dialogue to be developed with participants about their friendships. From the interviews, the main data extracted were: i) number of friendships, and ii) if they had a boyfriend/girlfriend. Inter-rater reliability was calculated from five randomly assigned interviews. Cohen's kappa (Cohen, 1960) yielded a reliability coefficient of 0.71 for friendships and 1.0 for boyfriend/girlfriend data.

Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 1999). For the present study, participants' intellectual ability was ascertained using the two-subset form of the Wechsler Abbreviated Scale of Intelligence: Vocabulary and Matrix

Reasoning subscales (WASI-II; Wechsler, 1999). The WASI-II is nationally standardised, and yields Verbal, Performance and Full Scale IQ scores. Correlations between the WASI-II and the WAIS-III are adequate (0.88 for Vocabulary, 0.66 for Matrix Reasoning).

Procedure

Ethical permission for the study was obtained from the local National Health Service Research Ethics Committee. Written informed consent was obtained from all participants. The interviews were carried out by a female researcher (first author), and lasted for an average of 47 minutes (25 to 54 minutes), and were conducted in a quiet, undisturbed room at the college or school the participant attended. The health knowledge questionnaire was administered first, with each subscale being followed by the sources of information questionnaire. Following this, social network data was collected. To avoid questions being too personal or threatening and to facilitate rapport and participant confidence, the questionnaire always began with the healthy eating and alcohol sections, and finished with more private and sensitive sexual health topics. To prevent the interviews being perceived as a test-like situation, the Wechsler Abbreviated Scale of Intelligence (WASI-II), used as an assessment of intellectual functioning, was administered at the end of the interview. The questionnaires were administered over one or two sessions, depending upon the concentration of the participant.

All answers were written onto the response sheets during the interview. After the interview, participants were given an opportunity to discuss the topics further. The majority of participants made additional comments at this time about the experience of taking part in the interview and asked how the data was to be used. Observations made during the interviews suggested that although a few participants became embarrassed whilst discussing certain topics, in particular sexual intercourse, no one became distressed or asked to terminate their interviews. Discussions with college tutors and school teachers suggested that participants were not anxious or distressed after being interviewed and, overall, found it to be a positive experience.

Results

All participants completed the healthy eating and alcohol questionnaire and 82 the pregnancy/contraception questionnaire. The reasons for one participant failing to complete all three of the questionnaires was because they had left college by the time of the second visit to complete the measures.

Analysis

The Kolmogorov-Smirnov test and normal Q-Q plots confirmed that the data deviated significantly from normality. Neither the removal of outliers or the transformation of the data through using natural logs or square roots resulted in normally distributed data, hence non-parametric tests were used. As this was an exploratory study, a conservative approach was taken to conducting pairwise comparisons between the three groups. To explore any differences in knowledge between young people with and without disabilities in the four health areas, the Kruskal-Wallis One Way Analysis of Variance for independent groups was used. This was followed by Mann-Whitney tests to establish where any differences were, using the modified Bonferroni procedure for multiple tests of significance.

Social Network Data

Table 2 shows that the participants with intellectual disabilities and those with physical disabilities had impoverished social networks when compared to the group without disabilities. These young people reported having fewer close friendships outside of school/college (medians: ND: 7, ID: 3, PD: 3, χ^2=26.894; p=0.001). Pairwise comparisons revealed that the ND group reported having more friends outside of school/college than the ID group (z=-5.054; p=0.001) and the PD group (z=-3.622; p=0.001). There were no differences between the two disability groups (z=-0.056; p= 1.0 r).In addition, whereas 17 out of the 31 participants in the group without disabilities said they had a boyfriend or girlfriend, this compared to only two participants from the other groups.

Table 2 about here

Health Knowledge

Healthy Eating: As illustrated in table 3, there were significant differences between the groups' knowledge of healthy eating ($\chi 2$ = 11.090; p=0.004). The ID group was less knowledgeable than either the ND (z = -3.137; p=0.002) or the PD group (z=-2.175; p=0.030) who in turn performed similarly to one another (z = -1.193; p=0.233). Data tended to be negatively skewed, with participants generally scoring at the higher end of the scale. This was most marked for the ND group for whom 6 participants (19.4%) achieved the maximum score, compared to 1 participant in the PD group and none in the ID group.

Overall, the young people were quite knowledgeable about healthy eating and as expected, group differences were minimal. However, it was noteworthy that the majority of young people in the ID group and a large proportion of the PD group found it difficult to grasp the concept of a balanced diet. Only one participant in the ID group and 13 participants (56.5%) from the PD group knew that just eating salad would be unhealthy, compared to 28 participants (90.3%) in the ND group.

Alcohol: The ND group were the most knowledgeable about alcohol, as shown in table 3, followed by the PD group and the ID group ($\chi 2 = 14.841$; $p = 0.001$). The ND and PD groups had significantly higher levels of alcohol knowledge than the ID group ($z = -3.560$; $p=0.001$ and $z=-2.739$; $p=0.006$ respectively). There were no significant differences between the ND and PD groups ($z=–1.309$; $p=0.191$). However, in the ND group, 9 participants (29%) achieved the maximum score, compared to 3 participants in the PD group and 1 in the ID group. There was a greater variance in knowledge scores for the ID group.

Overall, knowledge about the relative strengths of different alcoholic drinks and recommended drinking limits was good. However, several participants in each group thought it was healthier to ‘binge drink’ than to spread the amount of alcohol consumed throughout the week. The most commonly held misconception in relation to alcohol consumption, shared across the three groups, was that either having something to eat or drinking coffee would help someone to sober up.

Table 3 about here

Pregnancy and contraception: As table 3 shows, there were significant differences between the groups' knowledge of pregnancy and contraception (median = 6, $\chi 2$ = 33.625; p=0.001). This time the ND group scored significantly higher than both the ID group (–5.344; p=0.001) and the PD group (z=-4.242; p=0.001). There were no differences between the PD and ID groups' knowledge (z=1.674; p=0.094). Just over half of the participants in the ND group achieved a maximum score (16), compared to one ID participant and two PD participants. There was also much greater variance in knowledge scores of the ID and PD groups.

The most commonly held misconceptions by the two groups with disabilities included the beliefs that sexual intercourse hade to occur more than once for someone to become pregnant and that the contraceptive pill prevented HIV. They were unsure if the condom could prevent STIs. Other areas of confusion for the young people with disabilities were whether a new condom should be used at each sexual intercourse act and the role of the male orgasm in pregnancy.

Sources of Information

As shown in table 4, significantly more of the group without disabilities reported having spoken to friends about healthy eating, alcohol or pregnancy/contraception than participants in either of the other groups. Young people without disabilities were also significantly more likely to report having spoken to family members or health professionals about pregnancy/contraception than the other two groups. Differences between the ID and PD groups were minimal.

As table 4 shows, a number of participants in the group without disabilities reported learning about health from sources not included in the questionnaire, such as learning about nutrition from reading food packets and attending sports clubs.

Personal experience was also an important avenue for learning about health, such as discovering the effects of alcohol and gaining knowledge about pregnancy/contraception from personal relationships. The latter was only cited by participants from the group without disabilities.

Gender

Owing to the small numbers in each group, formal statistics could not be applied to examine gender differences in health knowledge, social network data or sources of information. However, examination of the median scores for each group by gender did not reveal any differences in male and females' knowledge about healthy eating, alcohol or pregnancy/contraception.

Table 4 about here

Discussion

Cognitive ability seemed to play a role in determining knowledge of healthy eating and alcohol, as it was only the participants with intellectual disabilities who had significantly lower knowledge in these areas. This is consistent with past findings that people with intellectual disabilities have poorer health understanding (Moore & McGillivray, 2003; Jobling & Cuskelly, 2006), because they find it harder to grasp key health messages. However, cognitive impairments alone cannot account for the finding that participants with intellectual disabilities and those with physical disabilities (and no cognitive impairments) had significantly poorer knowledge regarding pregnancy/contraception than their peers without disabilities. Both groups of participants with disabilities were also found to have very limited social networks and more limited access to sexual health information. Thus, poorer social engagement may have contributed to the participants with disabilities' lack of knowledge around sexual matters.

One interpretation of these findings is that different kinds of health knowledge are linked to different forms of social behaviour and modes of transmission. Social networks may have had the greatest impact when it came to the young people with disabilities' understanding of the topics of pregnancy and contraception, more private and personal issues (Gougeon, 2009). However, it needs to born in mind that this is an exploratory study and social networks were only one of a number of factors likely to have influenced the participants' developing knowledge of sexual matters.

Sources of information, also examined in this study, may also have contributed to different pattern of health knowledge across the groups of participants. Young people without disabilities reported relying on informal routes to learn about pregnancy and contraception, such as casual and spontaneous discussion with peers and talking with family members. They also used health professionals more and a number of them said that they learned through experience. These were not always viable options for the young people with disabilities in the current study, who described impoverished social networks and said they accessed fewer sources of health information. Moreover, visiting health professionals to obtain information about sexual matters or to learn from experience of intimate relationships requires a degree of autonomy and professionals recognising the person's adult status (Gougeon, 2009). Young people with disabilities may also find it harder to act autonomously, as they spend a large proportion of their time under the supervision of adults (Ailey et al, 2003).

Consistent with other research in this area, the young people with disabilities did not compensate for their lack of peer support by talking more with family members (Cheng and Udry, 2003; Morrison, 2006; Pownall et al, 2011). Whereas the majority of the group without disabilities had discussed pregnancy/contraception with their family, this compared to approximately a third of the participants with intellectual and physical disabilities. In contrast, a similar proportion of participants from all groups reported talking to their family about alcohol or healthy eating. There are likely to be a number of reasons for the lack of parent-child communication about sexual matters (Cheng and Udry, 2003; Morrison 2006; Pownall et al, 2011). Nonetheless, by failing to discuss such matters, parents may be inadvertently conveying negative messages about sexuality to their child (Jahoda and Pownall, 2014).

Implications for Policy and Practice

Having a better understanding of young people with disabilities' social networks and sources of information about sexual matters, could also help with the delivery of more effective sex education (Emerson &McVilly, 2004; McVilly et al., 2006a, 2006b). For example, to ensure that young people with disabilities obtain better access to information from health professionals, a telling change might be to make sexual health services adopt a more proactive approach to working with young people who have intellectual disabilities. This is likely to involve making links between sexual health services and schools or colleges (Fraser and Sim, 2007). Moreover as Gougeon (2009) suggests, schools might need to adopt a more positive stance to the sex education of young people with intellectual disabilities. Recognising that young people with intellectual disabilities will want to enjoy sexual relationships as they move towards adulthood means using more effective and explicit ways of delivering information on topics like pregnancy and contraception. Gougeon (2009) also proposed that educators need to be more conscious of she refers to as the hidden curriculum, that takes place through informal learning with peers. If adolescents lack such opportunities then greater efforts may be required to help young people with disabilities form and maintain social relationships. Within schools and educational settings, peer led approaches to learning about sexual matters may prove helpful. Outside school, young people with intellectual disabilities are likely to remain dependent on their families for day-to-day support. Therefore it is likely that helping parents to address this aspect of their offspring's development would be key element of a sex education strategy (Pownall et al, 2012).

Apart from school, the most common source of sexual information for the participants with disabilities was the media. Owing to a lack of literacy skills, this meant television for the participants with intellectual disabilities. The problem with relying on information from portrayals on television or in films, is that they are often far removed from individuals' own experiences (McCarthy, 1999). Having others to talk to can help young people to sort through the sometimes highly confusing and contradictory messages they receive about sexual matters. Sex education may also have a role in helping to dispel myths and confusions.

Limitations

This exploratory study has attempted to examine the complex relationship between social engagement and private (pregnancy/contraception) health knowledge.

Given that the participants with physical disabilities were younger than the other two groups of participants, it might have been this age difference rather than their limited social networks, that accounted for their poorer knowledge of pregnancy/ contraception. This possible confound means that the association between social networks and an understanding of pregnancy/contraception should be treated with caution.

Another drawback was the failure to collect data about the participants' reported engagement in behaviours linked to the health topics being investigated. There was a concern that asking for such personal information from potential participants may have made them reluctant to take part in the study. Nevertheless, a lack of data about how the participants actually behave and the nature of their own perception, limits the conclusions that can be drawn. Future work could build upon the methods developed in this study and use a mixed methods approach to examine the relationship between knowledge, attitudes and behaviour. Having both the questionnaire data and the participants' own accounts of their behaviour and experience would provide a more holistic picture.

Gender has been identified as a salient variable relating to young people's sexual knowledge, attitudes and behaviours (Leland & Barth 1992; Kraft 1993; Hansen & Skjeldestad 2003, Jahoda and Pownall, 2014). Yet gender differences were not found in the current study. One explanation for this is that whilst different health topics were covered, including sexuality, none were dealt with in sufficient depth for gender differences to emerge. Thus, the use of more detailed questionnaires and having a larger cohort might allow gender differences to be examined.

Another major limitation is that the measures used in the study were subject to minimal psychometric validation. This was because existing measures were not appropriate to the study's aims and design, and the measures used were carefully piloted to ensure they were engaging and meaningful to the target participants. Further psychometric validation of the measures would be an important first step in any future study of this nature.

Conclusions

There is growing concern about health inequalities faced by marginalised groups in society, including those with disabilities. To address these inequalities effectively it is important to understand how these gaps arise. The findings from this study suggest that a lack of social engagement may be a contributory factor to the poorer sexual understanding of young people with intellectual disabilities. This is difficult to address and will require a multifaceted approach that goes beyond providing formal sex education and includes working with families and fostering the peer relationships of people with intellectual disabilities.

References

Ackard, D. M., & Neumark-Sztainer, D. (2001). Health care information sources for adolescents: Age and gender differences on use, concerns, and needs. *Journal of Adolescent Health*, 29, 170–176.

Ailey, S. H., Marks, B. A., Crisp, C. and Hahn, J. E. (2003) Promoting sexuality across the life span for individuals with intellectual and developmental disabilities. *Nursing Clinics of North America*, **38**, 229-252.

Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T. and Bukovy, G. (1999) Sexuality and the adolescent with a physical disability: understandings and misunderstandings. *Issues in Comprehensive Pediatric Nursing*, 22, 183-196.

Blum, R., Resnick, M., Nelson, R. and St Germaine, A. (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. Pediatrics, 88, 280-285.

Bremner, P., Burnett, J., Mistral, W., Nunney, F. and Ravat, M. (2011) *Young people, alcohol and influences*. The Joseph Rowntree Foundation: York.

Carstairs, V. & Morris, R. (1991) *Deprivation and Health in Scotland*. Aberdeen: Aberdeen University Press.

Cheng, M. M. &Udry, J. R. (2002) Sexual behaviors of physically disabled adolescents in the United States. *Journal of Adolescent Health*, 31, 48-58.

Cheng, M. M. &Udry, J. R. (2003) How much do mentally disabled adolescents know about sex and birth control? *Adolescent and Family Health*, 3, 28-38.

Cheng, M. M. &Udry, J. R. (2005) Sexual experiences of adolescents with low cognitive abilities in the US. *Journal of Development and Physical Disability*, 17, 155-172.

Cohen, J. (1960) A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20, 37-46.

Edmonson, B., McCombs, K. & Wish, J. (1979) What retarded adults believe about sex. American Journal of Mental Deficiency, 84, 11-18.

Emerson, E (2012) Commentary: childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *Journal of Intellectual Disability Research,* doi: 10.1111/j.1365-2788.2012.01577.x

Emerson, E. & Baines, S. (2010) Health inequalities and people with learning disabilities in the UK: 2010. *Durham: Improving Health & Lives*: Learning Disabilities Observatory.

Emerson, E. & Baines, S. (2011) Health inequalities and people with learning disabilities in the UK. *Tizard Learning Disability Review* 16: 42–48.

Emerson, E. & Hatton, C. (2007a). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. *Journal of Intellectual Disability Research*, 51(11):866-874.

Emerson, E. & Hatton, C. (2007b). The contribution of socio-economic position to the health inequalities faced by children and adolescents with intellectual disabilities in Britain. *American Journal on Mental Retardation,* 112(2):140-150.

Emerson, E. & Hatton, C. (2007c). The mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry,* 191:493-499.

Emerson, E., Madden, R., Robertson, J., Graham, H., Hatton, C., & Llewellyn G. (2009). Intellectual and Physical Disability, Social Mobility, Social Inclusion & Health: Background paper for the Marmot Review. Lancaster: Centre for Disability Research, Lancaster University.

Emerson, E. and McVilly, K. (2004) Friendship activities of adults with learning disabilities in supported accommodation. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-7.

Fraser, S. and Sim, J. (2007) *The Sexual Health Needs of Young People with Learning Disabilities*. Edinburgh: Health Scotland.

Galea, J., Butler, J. & Iacono, T. (2004) The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 29, 350-365.

Golden, E., & Hatcher, J. (1997) Nutrition knowledge and obesity of adults in community residences. *Mental Retardation*, 35, 177-184.

Gordon, P. A., Tschopp, M. K., Feldman, D. (2004) Addressing issues of sexuality with adolescents with disabilities. Child and Adolescent Social Work Journal, 21, 513-527.

Gougeon, N., A. (2009) Sexuality education for studnets with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education*, 9, 277-291

Heal, L. W. and Sigelman, C. K. (1995) Response bias in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research*, 39, 331-340.

Health Scotland (2008) *A Review of Sex and Relationships Education in Scottish Secondary Schools*. Health Scotland: Edinburgh.

Illingworth, K., Moore, K. & McGillivray, J. (2003) The development of the nutrition and activity knowledge scale for use with people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 159-166.

Isler, A., Tas, F., Beytut, D., & Conk, Z. (2009).Sexuality in adolescents with intellectual disabilities. Sexuality and Disability, 27, 27–34.

Jahoda, A., & Pownall, J.D. (2014) Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers. *Journal of Intellectual Disability Research*, 58, 430-441.

Jobling, A. & Cuskelly, M. (2006) Young people with Down’s syndrome: a preliminary investigation of health knowledge and associated behaviours. *Journal of Intellectual and Developmental Disabilities*, 31, 210-8.

Kerr M. (2004) Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment*, 10, 200-06.

Learning and Teaching Scotland (2000) Health Education: 5-14 National Guidelines (5-14 Guidelines) *Learning& Teaching Scotland*. Available at: http://www.ltscotland.org.uk/5to14/guidelines/index.asp

Learning and Teaching Scotland (LTS) (1998) *The Health Education for Living Project (HELP)*. Scottish Office and Strathclyde Education Department.

Leung, C., M-K., Alexander K. C. Leung, A., K., C., Hon, L., L., E. and Albert Yim-Fai Kong, A. (2009) Fighting Tobacco Smoking - a Difficult but Not Impossible Battle, *International Journal of Environmental Research and Public Health,6*, 69-83; doi:10.3390/ijerph6010069

March, P. (1992). Do photographs help adults with severe mental handicap make choices? *The British Journal of Mental Subnormality*, 38, 122-128.

Marmot Review (2010) Fair Society, *Healthy Lives: Strategic Review of Health Inequalities in England Post 2010*. London

McCabe, M. P. & Cummins, R. A. (1996). The sexual knowledge, experience, feelings and needs of people with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 31, 13-21.

McCabe, M. P. (1999) Sexual Knowledge, Experience and Feelings Among People with Disability. *Sexuality and Disability*, 17, 157-170.

McCabe, M. P., Cummins, R. A. and Reid, S. B. (1994) An empirical study of the sexual abuse of people with intellectual disability. *Journal of Sexuality and Disability*, **12**, 297-306.

McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers.

McCarthy, M. (2009a) Contraception and Women with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 363-369.

McCarthy, M. (2009b) ‘I have the jab so I can't be blamed for getting pregnant’: Contraception and Women with Learning Disabilities. *Women's Studies International Forum*, 32, 198-208.

McCusker, C. G., Clare, I. C., Cullen, C. & Reep, J. (1993) Alcohol-related knowledge and attitudes in people with a mild learning disability: The effects of a ‘‘sensible drinking’’ group. *Journal of Community and Applied Social Psychology*, 3, 29-40.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R. and Burton-Smith, R. M. (2006a) ‘I Get by with a Little Help from my Friends’. Adults with Intellectual Disability Discuss Loneliness. *Journal of Applied Research in Intellectual Disabilities*, 19, 191-203.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R. and Burton-Smith, R. M. (2006b) Self-advocates have the last say on friendship. *Disability and Society*, **21**, 693-708.

Michie, A.M, Lindsay, W.R, Martin, V., & Grieve, A. (2006) Test of Counterfeit Deviance: A Comparison of Sexual Knowledge in Groups of Sex Offenders with Intellectual Disability and Controls. *Sexual Abuse: A Journal of Research and Treatment.* 18 , 271- 278.

Morrison, C. (2006). Draft Report: People Should Tell You Stuff. *A report from the TASC Agency on a consultation finding out more about what young people with a learning disability need when it comes to sexual health services*, NHS Health Scotland. Available at: www.healthscotland.com/uploads/documents/3289Final%20DRAFT%20Full%20Report%20People%20should%20tell%20you%20stuff.pdf (accessed 24 July 2007).

Murphy, G. (2016) Sexual relationships and adults with intellectual disabilities. In Alan Car, Christine Linehan, Gary O'Reilly, Patricia Noonan Walsh and John McEvoy (Eds.) *The Handbook of Intellectual Disability and Clinical Psychology Practice*. Routledge: New York

NHS Health Scotland. *People with Learning Disabilities in Scotland: Health Needs Assessment Report*. Glasgow: NHS Health Scotland, 2004.

Ogden, J. (2007) *Health psychology: A textbook* (4th ed.). Berkshire, England: Open University Press.

Ouellette-Kuntz H (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 18, 113-21.

Pownall, J.D. (2010). *Health Knowledge and Expected Outcomes of Risky Behaviour: A Comparative Study of Non-Disabled Adolescents and Young People with Intellectual and Physical Disabilities*. Unpublished PhD thesis, University of Glasgow. Available at: http://theses.gla.ac.uk/1701/

Pownall, J.D., Jahoda, A. , Hastings, R. and Kerr, L. (2011) Sexual Understanding and Development of Young People With Intellectual Disabilities:

Mothers' Perspectives of Within-Family Context. *American Journal on Intellectual and Developmental Disabilities*, 116 (3). pp. 205-219. ISSN 1944-7515

Pownall, J.D, Jahoda, Andrew , Hastings, R. and Kerr, L. (2012) Sexuality and Sex Education of Adolescents with Intellectual Disabilities: Mothers' Attitudes, Experiences, and Support Needs. *Intellectual and Developmental Disabilities*.

Psychological Corporation (1999) *Wechsler Abbreviated Scale of Intelligence Manual*. San Antonio: TX.

Rodgers, J. (1998) Whatever's on her plate: Food in the lives of people with learning disabilities. British Journal of Learning Disabilities, 26, 13-16.Siebelink, E. M., De Jong, M. D. T., Taal, E. & Roelvink, L. (2006) Sexuality and People with Intellectual Disabilities: Assessment of Knowledge, Attitudes, Experiences, and Needs. *Mental Retardation*, 44, 283-294.

Sigelman, C. K. and Budd, E. C. (1986) Pictures as an aid in questioning mentally retarded persons. Rehabilitation Counselling Bulletin, 29, 173-181.

Szollos, A. A. & McCabe, M. P. (1995) The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers. *Australia and New Zealand Journal of Developmental Disabilities*, 20, 205-222.

Talbot, T. J., & Langdon, P. E. (2006). A revised sexual knowledge assessment tool for people with intellectual disabilities: Is sexual knowledge related to sexual offending behaviour? *Journal of Intellectual Disability Research*, 50, 523-531

Townsley, R. (2004) The Road Ahead: *What Does the Literature Tell us About the Information Needs of Young People with Learning Difficulties and their Families at Transition?* Bristol: Norah Fry Research Centre.

Turk, V. &Burchell, S. (2003) Developing and evaluating personal health records for adults with learning disabilities. *Tizard Learning Disability Review,* 8, 33-41.

Van Schrojenstein Lantman-de Valk H. (2005) Health in People with Intellectual Disabilities: Current Knowledge and Gaps in Knowledge. *Journal of Applied Research in Intellectual Disabilities*, 18, 325–33.

Williams, P.G., Holmbeck, G., N. and Greenley, R., N. (2002) Adolescent Health Psychology. *Journal of Consulting and Clinical Psychology*, 70, 828-842.

Wish, J. R., McCombs, K. & Edmonson, B. (1979) *The Socio-Sexual Knowledge and Attitude Test*. Wood Dale, IL: Stoelting.

Table 1: ***Demographic Characteristics of Participants***

Group	**No Disability** (*n*31)				**ID Group** (*n*29)				**PD Group** (*n*23)			
	n	M	SD	%	n	M	SD	%	n	M	SD	%
Male	14				14				16			
Female	17				15				7			
IQ Score		97.1^a	5.72			59.4^b	5.24			95.7^a	6.58	
Age		18.7^a	1.42			18.5^a	1.35			16.7^b	0.75	
Socioeconomic status:												
DepCat^a												
Carstairs 1-2		4.68^a		16.1		5.14^a		13.8		4.61^a		13.0
Carstairs3-4				25.8				17.2				30.4
Carstairs5-7				58.1				68.9				56.5
Ethic Group												
White	31			100	29			100	22			96
Asian	0			0	0			0	1			4
Living Situation												
Family Home	26		84	27			93		23			100
Independent	5		16	0			0		0			0
Supported	0		0	2			7		0			0

Note. For IQ scores, age and SES (socio-economic status), means that do not share a superscript in common are significantly different from each other.

[a] A deprivation category (DepCat) for the mother was derived from the Carstairs score (Carstairs & Morris, 1991), which indexes neighbourhood deprivation on the basis of postal code sector of residence. The deprivation scores were based on the 2001 Census: Carstairs 1–2 = low, Carstairs 3–4 = medium, and Carstairs 5–7 = high.

Table 2: ***Summary Scores for Social Network Data***

	No Disability(*n*31)				**ID Group**(*n*29)				**PD Group**(*n*23)			
	n	M	SD	%	n	M	SD	%	n	M	SD	%
Number of Friends		8.7^{a}	5.1			3.5^{b}	1.9		4.48^{b}		4.7	
Boyfriend/Girlfriend												
Yes	17			55	2	7			2			9
No	14			45	27	93			21			91

Means that do not share a superscript in common are significantly different from each other

Table 3: ***Participants' Health Knowledge***

	No Disability (*n*31)	**ID Group** (*n*29)	**PD Group** (*n*23)
Healthy Eating			
Median	7^{a}	7^{b}	7^{a}
Range	5-9	4-8	4-9
SD	1.2	1	1.0
Alcohol			
Median	7^{a}	6^{b}	6^{a}
Range	5-8	3-8	5-8
SD	1.1	1.2	0.8
Pregnancy/Contraception			
Median	9^{a}	6^{b}	7^{b}
Range	6-9	3-9	4-9
SD	0.9	1.6	1.4

Note. For knowledge scores, medians that do not share a superscript in common are significantly different from each other.

Table 4: ***Summary Scores for Reported Sources of Information Data***

	No Disability (*n*31)		**ID Group** (*n*29*)		**PD Group** (*n*23)	
Information Source	n	ND-ID ǂ	n	ID-PD ǂ	n	ND-PD ǂ
Friends						
Healthy Eating	**24**^{a}	z=–2.068*	**15**^{b}	ns	**8**^{b}	z=–3.124*
Alcohol	**28**^{a}	z=-2.471*	**18**^{b}	ns	**14**^{b}	z=-2.550*
Contraception/pregnancy	**27** ^{a}	z=–-4.933**	**6** ^{b}	ns	**10** ^{b}	z=–-3.381**
Family						
Healthy Eating	27	ns	21	ns	14	ns
Alcohol	22	ns	17	ns	14	ns
Contraception/pregnancy	**25**^{a}	z=–-3.357**	**11**^{b}	ns	**8**^{b}	z=–-3.387**
School						
Healthy Eating	26	ns	26	ns	23	ns
Alcohol	**22**^{a}	ns	**24**^{a}	z=–2.804*	**23**^{b}	z=–2.154*
Contraception/pregnancy	23	ns	26	ns	22	ns
Health Professional						
Healthy Eating	12	ns	11	ns	7	ns
Alcohol	10	ns	13	ns	5	ns
Contraception/pregnancy	**21**^{a}	z=–-3.151*	**8**^{b}	ns	**5**^{b}	z=–-3.314*
Media						
Healthy Eating	27	ns	27	ns	23	ns
Alcohol	20	ns	20	ns	20	ns
Contraception/pregnancy	16	ns	15	ns	15	ns
Other Sources						
Healthy Eating						
Food Packets	3		0		0	
Sports Clubs	4		0		0	
Alcohol						
Personal Experience	6		0		2	
Contraception/pregnancy						
Personal Experience	7		0		0	

Note. Means that do not share a superscript in common are significantly different from each other. *In the ID group, 28 participants completed the contraception/pregnancy questionnaire.

ǂPairwise comparisons