



The Aawaaz project

Meeting the leisure needs of young people with a learning disability from South Asian communities

Raghu Raghavan

School of Health, Community and Education Studies
Northumbria University
Newcastle upon Tyne

Nicole Pawson

School of Health Studies
University of Bradford
Bradford



Acknowledgements

The Aawaaz project would not have been a success without the hard work of the young people who acted as co-researchers. We are very grateful both to them and to the young people and parents who participated in the focus groups. There are a number of organisations who helped us with the recruitment of young people for this project. We wish to thank: Bradford People First, Bradford College (Tony Scott, Kay Marshall, Ron Pearson), Haycliffe School (Di Freeman), Chapel Grange School (Sue Irving), Bolling Special School (Cath Robinson) and Children's Link (Steve Bowring).

We also wish to thank all the service providers for their commitment to this project and for their comments and help during the service provider meetings with the young people. We also wish to thank all the steering group members for their time and valuable input into this project. This project involved liaising with a number of parents. The help of Yasmin Ansari in contacting the parents and also in interpreting for their focus group discussions and meetings with service providers was greatly valued. We would also like to thank Laila Raza for interpreting at our final meeting.

We also acknowledge the tremendous support of Pippa Murray, IBK (Sheffield), Blake Williamson and his supporter, Asmaa Hans. Thanks also to Olawale Ismail (Bradford People First) and Steve McNally (Oxford Brookes University) who provided the training for the young people so that they could participate in this project as co-researchers. We wish to extend our thanks to Tam Carr from Acorn Video (Bradford) for her support with the filming, script-writing and production of the DVD for this project.

Finally we wish to thank Simon Bailey, Tom McDonough, David Bird, Jonathan Rennison and Isabella Bedi from Mencap for their funding and also their support and commitment towards this project.

We would like to thank the Big Lottery Fund (formerly the Community Fund), the Home Office and Section 64 for their financial support of this project.

Contents

Executive summary	5
Section 1	
About the project	9
Section 2	
Part 1: Methodology	15
Part 2: Training of co-researchers	21
Section 3	
Results	24
Section 4	
Discussion	45
Section 5	
Recommendations	54
References	56
Appendices	60



Executive summary

Young people with a learning disability from black and minority ethnic communities experience barriers in accessing leisure services. The Aawaaz project gave young people with a learning disability from South Asian communities in Bradford the chance to consult with their peers, parents and service providers about shaping the kind of leisure services that they want and need.

This project was conducted over a period of 18 months using an action research methodology and participatory research model. This involved recruiting seven young people with a learning disability from South Asian communities and enabling them to participate in this research as co-researchers through research training, facilitation and support. With the help of the researcher assistant, the co-researchers conducted focus group discussions involving other South Asian young people with a learning disability. The aim of the focus group discussions was to hear the views of other young people in relation to their leisure interests and needs. This was followed by focus group discussions with parents and carers of young people with a learning disability to hear their views about their children's access to and usage of leisure services.

In the final phase of the project, we organised five meetings with the co-researchers and key service providers who are responsible for leisure in Bradford. The theme of these meetings was to engage in dialogue and discussion about the leisure needs of young people with a learning disability from South Asian communities and identify an appropriate action plan for

how to shape and develop culturally sensitive services.

This report was commissioned by Mencap and funded by the National Lottery through the Big Lottery Fund (formerly the Community Fund).

Key findings

The young people and parents involved in the project highlighted a number of barriers that either prevented access to leisure or caused concerns about using leisure facilities. They also identified a number of key areas which could help to increase access to leisure services and improve provision. These are summarised below.

Barriers

- Young people expressed the view that having a physical disability and taking medication made it difficult for some young people to engage in leisure activities.
- Young people were also aware of family concerns about safety, lack of transport, and distance from the bus stop, which prevented them from accessing leisure opportunities independently.

- Young people identified lack of individual support, lack of information and limited number of friends as key barriers to accessing and using leisure services.
- Parents reported a general lack of information about leisure provision and were not always aware of the leisure activities provided by various services. Parents stated there was a lack of leisure pursuits for young people over 16 years of age.
- Parents were concerned about the lack of engagement by staff with the young people and the lack of stimulating activities.
- Parents reported a lack of community leisure provision and expressed their concern about the lack of appropriate funding for leisure services for young people.
- Parents said they were anxious about the vulnerability of young people and their safety when travelling and interacting with others.
- Parents said that leisure settings do not make the adaptations necessary to ensure they are suitable for people from South Asian cultures.

Key areas to improve access to leisure opportunities

- Young people expressed the need for greater support, particularly with transportation, help with taking

medication, writing, using money, doing things at the right time and knowing where and when to go.

- Some of the young people expressed the need for female-only groups in certain leisure pursuits, for example swimming.
- Some young people expressed the need for support when faced with bullying.
- Parents argued for greater awareness of disability issues among staff in leisure provision, and stressed there was a requirement for a better understanding of individual needs of young people.
- Parents reported a need for individual support for young people to use leisure services.
- Parents were concerned about the use of mixed-sex leisure activities such as swimming and football, and wished for single-sex options.

Involvement and participation

- Young people from South Asian communities, like other young people, were interested in a wide variety of leisure activities. This included activities such as swimming, cricket, football, tennis, snooker, bowling, boxing, going to the cinema, dancing, listening to Asian music, relaxing with friends, watching movies, sailing, going out to eat, ice-skating, henna tattooing, beauty therapy, arts and crafts.

Consultation

- Young people enjoyed their role as co-researchers and their participation in the various stages of this project enabled them to hear the views of their peers, parents and service providers.
- Young people from South Asian communities felt that they needed to be consulted by service providers in planning leisure services.
- Young people expressed the need for a social support group.
- Parents reported benefits from meeting other parents and suggested the need to form a parent support group for South Asian families.
- The service providers welcomed the opportunity to engage with the young people and their parents and carers.
- An action plan was formulated as a result of the meeting with young people and their parents and carers (this plan is available in the appendices).





1 About the project

Background

The Aawaaz project focused on leisure opportunities and services for young people with a learning disability from South Asian communities in Bradford. This project was commissioned by Mencap and funded by the Big Lottery Fund (formerly the Community Fund). A group of young people with a learning disability from South Asian communities played the most important role in the project by having a dialogue with other young people and parents as well as service providers and commissioners. The main purpose of the dialogue was to determine how best to adapt leisure services and provisions in order to make it easier for young people with a learning disability from South Asian communities to be included leisure opportunities.

Introduction

Over recent years the policy of ensuring good-quality services for people with a learning disability has developed to include the requirement that they should be supported to express their views about the services they use. The passing of the National Health Service and Community Care Act 1990 fostered the development of a consumer-led focus in relation to health and social services. The Act stipulates that “the local authority must consult the person and consider whether the individual has a carer and, where appropriate, consult them”.

Advances in the social position of people with a learning disability have led to a situation where research and evaluation studies are increasingly required to include the views and opinions of people with a learning disability. One key outcome of this shift is that some of the major funding bodies now insist on the inclusion of people with a learning disability in the development and undertaking of research as a condition of funding. This has produced new possibilities and new challenges for researchers, and it has real consequences for people working in health and social care (Gilbert, 2004).

Another major catalyst for change was the ‘Valuing People’ white paper (Department of Health, 2001), which called for an improvement of services so they not only meet the needs of these young people but also value them as citizens. In endeavouring to improve the quality of life of these individuals, it is important that these basic principles are addressed. The opportunity to make choices, and the extent to which these young people make decisions about their future, is paramount. The white paper (DoH, 2001) outlines the government’s strategy for improving the lives of people with a learning disability and their families. The agenda is based on the recognition of their rights as citizens to be socially included, have choice in their daily lives and have opportunities to achieve independence. ‘Valuing People’ was followed by ‘Valuing People Now’ 2008.

Legislation such as the Disability Discrimination Act 1995 and the Human Rights Act 1998 state that disabled young people have the right to be included in mainstream society and to have equal opportunities. A major source of frustration for people with disabilities lies in the gap between the rhetoric of the Disability Discrimination Act 1995 and their common experience of being denied access to public transport, buildings and open spaces. In order to address these, a Disability Task Force was set up in 1997. Further to this the Disability Rights Commission was established in 2000 with the aim of breaking down the barriers of discrimination against people with disabilities.

Policy initiatives such as the Quality Protects Programme in England (2000) and the National Service Framework for Children and Young People (Children First 2005) all aim to bridge the gap between legislative aspirations and the daily experience of vulnerable young people. In April 2005 a new Disability Discrimination Act was passed by parliament amending or extending existing provisions in the DDA 1995. Some of these have direct relevance to inclusion in leisure activities.

These changes included:

- making it unlawful for operators of transport vehicles to discriminate against people with disabilities
- making sure that private clubs with 25 or more members cannot keep people with disabilities out just because they have a disability
- ensuring that discrimination law covers all the activities of the public sector, requiring public bodies to promote equality of opportunity for people with disabilities.

Legislation and guidance across education, health, leisure and social services strengthens the expectation that professionals will consult with children and young people about decisions that affect them. For example, the Children Act 1989 requires authorities to ascertain children's wishes and feelings. This Act also stresses the importance of allowing young people with disabilities to have normal lives and to be given opportunities. More specifically for children and young people, Every Child Matters: Change for Children (Department of Education and Skills, 2003) is a new approach to the wellbeing of children and young people from birth to age 19.

The aim is for every child, whatever their background or their circumstances, to have the support they need in:

- being healthy
- staying safe
- enjoying and achieving
- making a positive contribution
- economic wellbeing.

The framework is also working towards the establishment of children's trusts, which proposes to which would integrate social care, education and health services. The effective involvement of children, young people and their families or carers in the development and running of all children's trusts is also a key objective.

It has also been recognised that young people with a learning disability from black and minority ethnic (BME) groups are under-represented in adult services compared to their white counterparts (Department of Health, 2001). They may experience even further isolation because many of these young people face greater inequalities and exclusion in employment, education and health (Mir et al, 2001). This phenomenon has been known as 'double disadvantage' or 'triple jeopardy'. Research has primarily focused on young people from a white background, paying less attention to young people from black and ethnic minority backgrounds. And while there has been research highlighting the barriers faced by black and minority ethnic families caring for a disabled child, it has not focussed on young people's views (Butt and Mirza, 1996).

This becomes relevant also for BME families as the UK population is becoming gradually more diverse and complex in terms of ethnicity, culture, language and religion. The 2001 Census showed that South Asian communities made up 4 per cent of the UK population and Pakistani and Bangladeshi communities made up 1.8 per cent of this

figure. In regard to Bradford, where the research was carried out, 14.5 per cent of the population is of Pakistani origin and 1.1 per cent of the population is of Bangladeshi origin. The focus, therefore in the present study, was consultation with young people with a learning disability and their parents from South Asian communities.

Importance of leisure opportunities

Previous research has highlighted the importance of leisure in facilitating the development of skills and adaptive behaviour. Involvement in leisure activities is an important aspect of most of our lives (Datillo & Schlein, 1994). Not only is it valuable as entertainment but it also provides a means to establish friendships with peers and contributes to better health and wellbeing.

- It has been found that young people with a learning disability tend to participate in home-based activities and may often be excluded from mainstream activities (McKonkey & McGinley, 1990; Azmi et al, 1997).
- Most leisure activities tend to be of a passive, dependent nature involving such things as watching TV or being taken to visit family members. However leisure is a key area in paving the way towards full community inclusion and participation.
- It becomes more significant for disabled young people when barriers to full participation in education and employment result in them having more

time for leisure pursuits while simultaneously experiencing greater difficulty in accessing leisure services, activities and pastimes (Murray, 2002).

- Leisure may also provide emotional benefits for people with a learning disability (Browder & Cooper, 1994; Williams & Dattilo, 1997).

More attention needs to be given to the friendship activities of people with a learning disability (Emerson and McVilly, 2004). Duvdenney (2002) found that people with a learning disability who participated in integrated recreation activities had a higher physical self-concept and satisfaction than their counterparts who participated in segregated leisure pursuits.

For many individuals with a learning disability, the family is the sole source of social support and they seldom, if ever, have friends in the neighbourhood (Solish et al 2003). They are often perceived as less socially competent and of lower social status than their peers without disabilities (Geisthardt et al 2002). Creating or finding opportunities to make friends and participate in activities may add significant stress to their daily lives. If young people with a learning disability are involved in social activities, the support needed is usually provided by parents (Solish et al ibid). Relationships with paid carers are often perceived by individuals with a learning disability as friendships (see Robertson et al 2001). A recent survey of

residential homes in Netherlands found that only 3.8 hours of leisure time on weekends were provided for people with a profound learning disability. The leisure activities were predominantly offered by professionals (Zijlstra & Vlaskamp, 2005).

There is generally limited access to leisure activities for people with a learning disability. Barriers such as a lack of friendships, a deficit in life skills and independence, and a deficiency in social skills, numeracy, time and money recognition have been identified (Browder & Cooper, 1994). Beart et al (2001) found barriers such as lack of transport and carer or friend support prevented people with a learning disability from accessing leisure. Reynold (2002) also found the major barrier to creative leisure participation was the funds required for the activity itself and for support staff.

The young person's experience of being disabled and their perceptions of inclusion have also received more attention from researchers. Murray (2002) consulted with over 100 disabled teenagers to uncover their experience of 'inclusive leisure'. Many felt that their experiences in both types of schools isolated them from non-disabled peers and made it difficult for them to make friends. Most young people wanted to participate in leisure in a normal way. However, lack of appropriate support was a major barrier to involvement. Many of the young people reported experiences of

isolation, loneliness and exclusion. Disabled young people felt that their experiences at school/college strongly affected their access to friends and leisure outside school.

There has been limited research with young people from BME communities. The research has alluded to young people experiencing pervasive racism and stigma throughout their lives, known as 'double discrimination'. Adolescents and adults with a learning disability from South Asian communities were consulted about their views in relation to specific areas of their lives. It was found that 'double discrimination' led to a lack of culturally appropriate services, limited friendships and a lack of leisure activities (Azmi et al, 1997). Most young people had experiences of disability that were similar to those of their white peers, and some were discriminated against because of their ethnicity and felt excluded from services because their cultural needs were not being met (Hussain et al, 2002). Findings suggest that many of the young people were socially isolated and many had negative experiences of school.

Bignall et al (2002) recruited young people from Asian, Caribbean and African backgrounds to participate in peer support groups. The young people stated that participation in these groups allowed them greater opportunities to explore their ethnicity and to meet and be with young people similar to themselves. Attending a peer support group was important in the

lives of these young people with disabilities. Participation in the groups allowed the young people to gain emotional support, make friends, learn new skills and to enjoy themselves. The authors found that a number of factors prevented young people from attending peer support groups. These included transport, venue and money.

It is evident from the literature that greater consultation is needed with young people with a learning disability, particularly in black and minority ethnic communities. As a result, this project focused on planning leisure activities for young people within South Asian communities as these communities have a higher representation in the city of Bradford.





2 i) Methodology

Involvement of people with a learning disability in shaping the services that they require and in discussing the matters that concern them is vital to planning and providing inclusive services. Their personal accounts may guide the way in which services are provided to meet their needs. Traditional research methods have discriminated against people with a learning disability, seldom seeking their views but often consulting others on their behalf (Ramcharan and Grant, 1994; Booth, 1996). They have been historically viewed as a hard-to-reach group, as communication and language problems, challenging behaviour and complex health needs may be present.

This was an action research project concerning leisure opportunities for young people with a learning disability from South Asian communities (to include Pakistani, Indian and Bangladeshi groups) in Bradford. This project was based on a participatory research model, meaning that it was designed to involve young people with a learning disability as co-researchers and facilitators. Participatory research seeks to empower and change the traditional model of research, which is that of expert/subject. The model starts from the position that participants have a right to be consulted and involved in research that concerns their lives. Participatory research involves understanding the experiences of the co-researchers and relies on qualitative methods (Walmsley, 2001). Strategies that facilitate participatory research may include

choosing a topic worthy of research by people with a learning disability, asking these individuals to be consultants and providing support, training and payment (Ward and Simons, 1998; Williams, 1999). In participatory research, the research topic may be chosen by the non-disabled researchers or people with a learning disability. They work together to achieve a collective understanding of the problem.

Ethical approval

Undertaking qualitative research with young people with a learning disability poses many ethical dilemmas. In any research project involving vulnerable groups of participants, ethical approval has to be obtained. In social research, the principles of ethics relate to the prevention of harm, informed consent, issues of confidentiality, trust, reciprocity and privacy (Ramcharan and Cutcliffe, 2001). Before this project could be undertaken, ethical approval was sought from the Local Ethics Committee (LREC) in Bradford. The committee required a copy of the research proposal, the information sheets for the carers and young people, and a copy of the consent form. Questions of informed consent arose. They also raised issues of language and communication. In order to ensure that the young people and their carers had informed consent/assent, an information DVD featuring young people acting out aspects of the research was produced and shown to them before gaining consent.

Important questions also had to be considered before undertaking the research.

“How will the research be useful? How will it contribute to the lives of the people with learning disabilities? Will the research bring about change? Have people with learning disabilities been involved in establishing the aims and purpose of the research? Could research participants be harmed in any way through involvement?” (Lewis & Connors, 2004, p 192)

The issues of privacy, confidentiality, trust and reciprocity again were paramount. The researcher has a responsibility to participants to ensure this occurs. The young people and their family place their trust in the researcher once they sign the consent form. Trust was established by first visiting the families for consent and answering any questions they had. They were reassured that it was their choice to be involved and they were free to withdraw at any time. Ethical approval was given subject to amendments.

Rationale

The rationale for the Aawaaz project was based on the need to:

- increase leisure opportunities/services for young people with a learning disability from South Asian communities

- increase representation of young people with a learning disability from South Asian communities in planning future services, including leisure services
- promote participation and social inclusion as identified by ‘Valuing People’ white paper (DoH, 2001).

Aim

- To involve young people with a learning disability from South Asian communities in working collaboratively with service providers to develop appropriate and sustainable leisure opportunities.

Objectives

- To empower and encourage dialogue between young people, parents and providers.
- To raise awareness among service providers of the needs of young people with a learning disability from South Asian communities.
- To help service providers improve leisure opportunities for young people with a learning disability from South Asian communities.
- To develop good practice in working with young people, their families and service agencies.
- To provide an ongoing reference group for providers to include in the planning stage.

- To enable service providers to develop services that meet the needs of young people with a learning disability from South Asian communities in Bradford and target their resources more effectively.

Method

This project involved the following five stages:

1. The recruitment of young people from South Asian communities as co-researchers, and the provision of the necessary training for them.
2. The setting up and running of focus group discussions (facilitated by the co-researchers) with young people with a learning disability from South Asian communities.
3. The setting up and running of a focus group with young women with severe and complex learning disabilities from South Asian communities.
4. The setting up and running of focus group discussions with parents and other family carers.
5. The holding of meetings with service commissioners and providers (facilitated by the co-researchers).

Focus group discussions were used as the main format of data collection and consultation with young people with a learning disability, their families and service providers. The focus group discussions with

young people were facilitated by seven young people with a learning disability who were trained as co-researchers (see section 3). A number of studies have used this approach to facilitate participation (see Stalker, 1998; Rogers, 1999). The researcher played a role in supporting the co-researchers through the group process, assistance that has been acknowledged as fundamental in enabling young people with a learning disability to develop skills, experience and confidence in the research process (see Gilbert, 2004). Barr et al (2003) suggest that focus group discussions may help participants gain confidence, create safe and non-threatening environments and provide peer support. Recently, Williams and Helsop (2005) conducted focus group discussions with young people regarding their emotional needs as they faced transition. In their feedback about their involvement, many of the young people said they felt more confident and that the occasion had given them the opportunity to talk about their feelings.

Artwork materials, flip charts and warm up exercises were used in the focus groups to engage the young people and to ensure the process was both flexible and enjoyable. It was important to use innovative approaches to increase the participation of the young people. This also allowed for flexibility around their individual needs and abilities (see Stalker & Connors, 2003). Lewis and Porter (2004) set out clear guidelines for researchers undertaking research with

children with a learning disability as this process raises both ethical and challenging methodological considerations. They suggest that researchers should also use complementary methods to explore views that are both imaginative and innovative.

Focus group discussions may also be used with those who have limited language through the use of pictures and symbols. An adapted version of 'Talking Mats' (Pawson et al, 2005) was used with women with profound and multiple learning disabilities. 'Talking Mats' (Cameron & Murphy, 2002) is a pictorial framework, which has been used as a communication tool for exploring the views of young people. The tool, which uses symbols to represent themes, options and emotions, has been used successfully with young people who do not use verbal language to communicate (see Rabiee et al, 2005).

There have been concerns about the validity and reliability of data arising from interviews and focus group discussions with people with a learning disability. In some circumstances a tendency to acquiesce has been noted (Sigelman et al, 1981). To combat this, and to ensure people's lives, experiences and views are represented accurately, it is helpful to interview someone who knows the participant well in order to identify important people and events in their lives. Equipped with these reference points, the interviewer is then able both to make the interviewee feel more comfortable and

also to cross check his or her responses for reliability. So for these reasons we felt it was important in the project to obtain information from parents before focus group discussions with the young people.

Recruitment

Information sheets about the Aawaaz project were produced in Urdu, Hindi, Gujarati, Bengali and Punjabi. These were sent out to parents and young people via the Early Years and Childcare database of families caring for young people with a learning disability. The information sheets were also sent out to families already known to the researchers. An information DVD featuring five young people with a learning disability was produced. The DVD featured the young people in a mock focus group, training and meeting with the service providers. The DVD was produced in the five South Asian languages listed above.

The first stage of the recruitment process focused on identifying young people for training to become co-researchers. Seven young people, four males and three females, were recruited through a local further education college, Bradford People First and a local special school.

The age groups and ethnic backgrounds are displayed in table 1 below.

Table 1: age group and religion of co-researchers

	Age group	
	16-19	20-24
Pakistani Muslim	1	5
Indian Hindu	1	0
Total	2	5

Recruitment of young people to focus groups

The recruitment of young people for the focus group discussions occurred over a longer period, from June to December 2006. There were 24 young people (15 males and 9 females) recruited from three special schools, one mainstream school and a local further education college.

Six focus group discussions were conducted in the schools and college between September 2006 to January 2007 at the convenience of the young people, teachers and tutors.

The age groups and ethnic backgrounds are displayed in table 2 below.

Table 2: age group and religion of participants in the focus group discussions

	Age group		
	12.5-15	16-19	20-22
Pakistani Muslim	5	12	3
Indian Hindu	0	2	1
Indian Muslim	0	1	0
Total	5	15	4

Recruitment issues

The group that posed the most difficulty in recruitment were the young women with profound and multiple learning disabilities. Initially a local day service centre in Bradford was approached because they run a special group for South Asian women with complex disabilities. The DVD was shown to the young women who expressed an interest in the project. The centre agreed to send out information sheets to their parents on our behalf. However, the response rate was low. Due to confidentiality issues the centre could not divulge contact details for follow up phone calls to be made.

Consequently, another special school, which caters for young people with complex disabilities, was approached. The information leaflets were sent through the schools to parents; however the response

rate was again low. Issues of data protection also arose and the school would not allow follow up calls to be made. Therefore consent for only three young women with profound and multiple learning disabilities was given, and these contacts were already known to the researchers. Only two of these young women were present for the focus group because one of them was not in school that day.

Recruitment of parents

A total of 17 parents, 11 females and 6 males, attended 4 focus groups, which were held at the School of Health Studies. See table 3 below.

Table 3: age range and religion of parents who attended focus groups

	Age range	
	39-49	50-70
Pakistani Muslim	10	6
Indian Hindu	1	0
Total	11	6

The numbers of parents were lower because some parents were not able to attend the focus group discussions due to other commitments.

Analysis

Qualitative analysis uses analytical categories to describe and explain social phenomena (Pope et al, 2000). The young people’s responses were analysed by the co-researchers and the research assistant. This involved going through the data recorded on the flip charts and artwork, arranging them into common themes and categories. This process was very straightforward because the data was represented in the form of artwork and recorded notes on flip charts. Individual meetings with parents, and parents’ focus group discussions, also served as a reliability check of the young people’s responses. Transcripts of the parent’s focus group discussions were content-analysed and arranged into major thematic headings. These main themes were checked for reliability at subsequent meetings with parents.

2 ii) Training of co-researchers

Research training of the young people took place in July and August 2006. This training was conducted over five half days during a period of two months and was facilitated by external consultants along with the research assistant (NP). This training focused on a variety of skills needed to consult with groups of young people. A variety of creative activities were explored to help consult young people with a learning disability about leisure activities. This involved artwork, a variety of games and role play. The training explored the co-researchers' experiences of leisure, prepared them for presentations and for working together as a

group. Confidence building and planning meetings were an important aspect of the training. Communication skills, preparing research questions and facilitating focus group discussions were also explored. The co-researchers provided feedback at the end of each day. Some of the elements they enjoyed were:

- the food
- arts and crafts
- spending time with each other
- having fun.



Welcome to our training day!

Activity: What are you good at?

The co-researchers said they were good at:

- talking
- saying hello
- time-keeping
- acting
- drawing
- taking notes.

Activity: Fozia presenting her collage of the things she likes to do, the people she loves and the places she likes to go.

Activity: Body rights; exploring what can help us do the things we like to do!

The co-researchers said the things that they wanted were:

- help with writing
- to have confidence in themselves
- help with thinking
- kindness and help from other people
- information so they can make choices
- help with talking and speaking to people.

Activity: Dream catcher; leisure time into dream time!

The co-researchers said the things that they wished for were:

- mendi before wedding
- halal food
- music
- a mansion, Ferrari and a fit woman
- lots of fresh air
- boys-only swimming sessions
- helpful staff
- friends to play cricket with.



We are the co-researchers

“I am 19 years old. I will be starting Bradford College in September. I am a very helpful person. I am now learning to travel by myself. I enjoy going to the Lake District and going out to restaurants. I missed my best friend when I left school before the summer holidays.”

Hammad

“My name is Fozia and I am 22 years old. I go to Barnardos once a week and I am looking for a training course. I like netball and swimming but I don't do them often. I can't go on my own because my parents worry.”

Fozia

“I am 18 years old. I like swimming, bowling, hockey and golf. I live with my Mum, Dad and my sister.”

Natasha

“I am 24 years old. I work at Mind the Gap Theatre Company. I go to the gym on Sunday morning; my Dad takes me and picks me up. I go swimming on Monday. I also go to People First on Friday, I take the bus there. I play football at home and I like listening to Bhangra music and watching Bollywood movies. I like going to weddings too!”

Israr

“I am 25 years old. I work in Miss Pennys but I don't get paid. I stack biscuits and sodas. I chill out and go to the shops. I see my cousins. It is important for me to go to the mosque and pray. I read the Quran every day. I go to the sports centre to play football and badminton with my brother. I play cricket in the street and we play tag and racing. I like to go out with Mum and Dad to visit the family. I don't like people taking the 'mick' out of my Mum and Dad or when they swear.”

Shabab

“I am 21 and I will be 22 soon. I am returning to college next week (September). I am clever. I took a year out of college. I like people in college and my course tutor. I like watching TV, listening to Asian music and going to weddings. I also like football and cricket. I would like to go swimming but for girls only. I love clothes, make-up and shoes.”

Aasma

“My name is Mohammed Amin, I am 23 years old. I like going out and playing outside. I like snooker, swimming and cricket. I do weight training at Richard Dunns two days a week. I can travel independently. I also keep pigeons at home and like watching movies like Kill Bill. I go to Shipley Resource Centre on Tuesday and Shipley College on a Friday.”

Mohammed

3 Results

Process

Regular meetings with co-researchers were held to prepare for each focus group with the young people. The co-researchers selected the warm up activities and questions for the focus groups. These meetings also involved practising for the focus group and assigning questions for each co-researcher to ask. The focus group discussions fostered peer group interaction and the sharing of experiences, giving the young people a rare opportunity to express themselves and to be listened to by people outside their immediate family. They also allowed the young people to build their confidence in speaking in groups while also letting them do enjoyable activities. The co-researchers also had unique insights and shared common experiences with the young people because they come from similar backgrounds and face similar challenges. Particular cultural past times that would not necessarily have been known to the research assistant, were also followed up by the co-researchers. For example, this included specific Bollywood movies, songs and Asian actors/actresses. For the co-researchers, revisiting their old schools and colleges was a bonus. Meeting with old teachers and tutors and explaining that they were conducting research at the University of Bradford also gave the co-researchers a strong sense of pride.

Each of these groups was run by two co-researchers with support from the research assistant (NP), as the co-

researchers often needed support and prompting. These focus group discussions took place in the schools and the local college. The focus group discussions were started off with warm-up exercises to allow the young people to feel more comfortable and relaxed. Initial questions were asked about defining leisure and the kinds of activities the young people enjoy doing in their spare time. The responses were recorded on flip charts. The young people also completed various types of artwork depicting the activities that were important to them and the barriers that prevented them from accessing leisure. They also discussed ways of increasing access to leisure opportunities.

Example of warm up activity:

Getting to know each other. A ball was passed around to each young person and whoever had the ball would introduce themselves.

Findings

The findings are presented in two main parts. First the findings from young people and parent focus group discussions are succinctly presented. The focus was on how to increase access, since the barriers have been well-documented in previous research (see Introduction). Secondly the findings from meetings with young people, parents and service providers are presented. Finally feedback from the co-researchers is presented in this section.

BIRMINGHAM SPORTS CENTRE



Part 1: focus groups

Focus groups with young people

The young people were interested in a wide variety of activities (see list below). However the majority of young people only participated through school, with special groups or with family members. Young people had little opportunity to engage in leisure activities independently or with peer group support.

Swimming, cricket, football, tennis, snooker, bowling, boxing, going to the cinema, dancing, listening to Asian music, relaxing with friends, watching movies, sailing, going out to eat, ice-skating, henna tattooing, beauty therapy, arts and crafts.

Barriers

The young people demonstrated considerable insight and knowledge about the reasons why their access to leisure provision was hindered. Overwhelming lack of adequate support was considered a main reason why young people were not involved in the activities they would otherwise like to participate in. The young people defined support in many ways. This included an individual to escort them to the activity and remain with them. Support also included ensuring the young person got there on time and arrived at the correct place.

Lack of transport was also discussed in every focus group. For some, public transport was not readily available, or they simply did not have support to use public transport.

Many young people relied on their parents to take them out; however with other parental commitments sometimes being pressing, this was not always possible. For example, a young person said, “the bus stop is too far from my house”. Many others like this young person are unable to use public transport due to the lack of support and adequate training.

The young people were very aware of family concerns over safety in the public domain and travelling without support. The young people also expressed the view that many of them were unable to travel independently and needed individual support. Fears of getting into trouble or being around individuals who were trouble makers were also reported.

“Family doesn’t let them go because they worry about them if anything may happen to them.”

“Parents won’t let me go to the shop on my own because it’s too dangerous.”

“People swearing, stay away from trouble.”

Some young people spoke about physical disabilities preventing them from accessing leisure facilities. This included hearing problems, physical mobility and concerns

about taking medication. One young person was concerned about not being able to hear cars when crossing the road. One young man was concerned about his medication making him feel dizzy and his ability to remember to take his medication without adequate support.

Lack of money to pay for an activity was also an issue for some young people. This related to money management skills - confidence in paying the right amount and being aware of the correct change.

Access facilitation

Young people reported that having greater support would facilitate access to leisure. They said they wanted support around the issues of taking medication, combating bullying, doing things at the right time, handling money and writing. Building up the young people's confidence in their ability to carry out these tasks is something that needs to be undertaken until the young people reach the point where they feel safe and confident enough to undertake them independently. Young people also require easy and accessible directions to the venue and time of activity. Other suggestions included having a mobile phone in case one got lost and the provision of easy-to-understand information leaflets about activities. Some young women specifically required a female-only group. Identifying with their cultural pastimes was also important to the young people. They enjoy Bhangra music, Bollywood movies, and henna tattooing.

The young people also recognised the need to help each other and to encourage other young people to become involved in leisure activities. The value of building friendships and peer group support was well recognised.

“Staff need to keep an eye and make sure they are not being picked on.”

“If you help other people you will get blessed. God will say you are doing good things.”

“Get more people in activities.”

“Ask people if they want to play.”

“Working as a team.”

The young people were very keen participants and reported enjoying the focus groups. It provided an opportunity for them to share their leisure interests with their peer group. They also reported that it helped them to feel more confident.

Focus group discussions with young women with profound and multiple learning disabilities

As referred to in the section about recruitment, there were difficulties recruiting young women with complex disabilities. Consequently only two young women participated. Only one of the young women had verbal language, however the other young woman was able to participate using non-verbal communication. The two co-researchers who facilitated this group were females. Due to language difficulties and

varied levels of understanding, an adapted version of 'Talking Mats' (Pawson et al, 2005) was used. 'Talking Mats' (Cameron & Murphy, 2002) is a pictorial framework, which has been used as a communication tool for exploring the views of young people. The tool relies on symbols representing themes, options and emotions. The young women were provided with pictures of various activities to choose from. In addition a flip chart was used to record responses. A ball was also brought along as a warm up game, however this proved to be of more interest to one of the young women. She was not keen to choose pictures but was happy to play ball games with the co-researchers and research assistant. She also had a support worker present who was able to understand her non-verbal communication and was aware of the activities she enjoyed participating in. The other young woman was able to choose pictures and also verbalise her leisure interests. She was also keen to demonstrate her enjoyment of football.

Focus group discussions with parents

“Children under 16 have opportunity to get different services but over 16 there is nothing available. When they reach adult age the need is greater. Children under 16 have access to services but over 16 they decrease.” Father



Process and findings

The focus group discussions with parents was run by the research assistant (NP) and an interpreter. Although many parents spoke some English they felt more comfortable speaking in their first language. The languages used were Urdu, Punjabi (impure) and Hindi. Parents discussed many issues that prevented access to leisure opportunities, many of which have been reported in the literature.

Lack of information and limited provision

Parents reported a general lack of information about leisure provision and said they were not aware of activities provided. They then made practical suggestions to improve information provision in order to reach out to the South Asian communities. Most parents suggested that having accessible staff on hand to provide support and to explain options would be very helpful.

Although it was felt that it may be useful to send out leaflets, sometimes the information may not be clear or may be complicated. It was suggested that a central office (one main point of contact with services) providing information about all disability issues with staff available to explain or to answer any queries would be very helpful. A venue where South Asian parents could meet, get to know each other and share information would also be welcomed. Home visits by professionals were also suggested as another way of getting information into the communities. Parents also suggested that information could be sent out through schools to ensure that it is disseminated to families caring for a young person with a learning disability.

Parents also recommended the use of local Asian radio stations to advertise various activities and events, citing a radio debate about autism some of them had listened to as proof of how effective this could be in reaching people.

“Most people don’t acknowledge autism and there is no word for autism.” Mother

Parents were also concerned with the lack of leisure provision for young people over 16. Overall parents were concerned that there were a limited amount of clubs for young people with a learning disability.

“There needs to be someone to speak to and to explain. Some people are uneducated and need an interpreter. Some people cannot read and so cannot read leaflets in Urdu either.”
Father

“A central office to provide information for all disabled children would be good. Information provided by community centres would also be helpful.” Father

For young people who were accessing a leisure service other issues were apparent. This included lack of engagement with young people by staff and lack of stimulating activities.

The lack of local community leisure provision was also a major issue. Problems with leisure schemes being terminated because of time-limited funding was also an issue.

“And even when he was going to the centre all he did was go into the TV corner or video and sat there for two hours. So they didn’t try to help him get involved in the group and play like football or play snooker. It was only when I went in and said to him (staff), can you get him on the snooker table please and away from the DVD, because I think that’s what most children do.”
Mother

“My daughter used to go to a scheme run by the church however they ran out of funding and that was the end of that.”

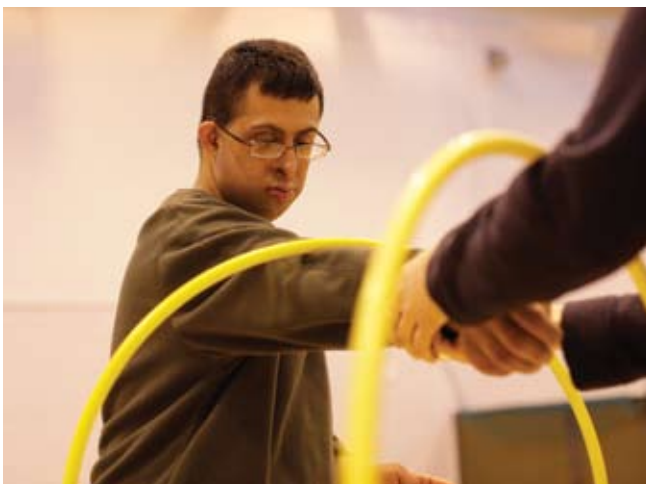
Father

“Finally they turned around and said we can’t take him anymore because we haven’t got funding and we can’t take special needs children.”

Mother

Disability awareness

Parents were very concerned about the lack of disability awareness of staff in services. They spoke about the need for disability awareness training for staff in mainstream leisure provision. It was felt that there is poor awareness about disability issues and a lack of staff confidence in relating to the young people. The concern that the young people were being supervised inadequately at some of these activities was also raised.



“We need staff training (for people who work with) children with learning disabilities. Normal children will learn to cooperate with children with learning disabilities and children with disabilities will try to follow what they are doing.”

Father

“They have a group of 15 children, at break time they just leave them at the table and let them eat. Children left to feed themselves.”

Father

For example, parents reported lack of individual support at public swimming pools for disabled young people. The private swimming classes were also too expensive for many parents. This left very few options for young people who enjoy swimming. Some parents were also concerned about disabled young people mixing with non-disabled young people without having adequate support. They were concerned about bullying. Conversely other parents felt it would benefit their children to be involved in inclusive opportunities. Raising awareness of disability issues and providing opportunities for disabled and non-disabled young people to socialise was considered a priority for some parents. These parents expressed the view that both disabled and non-disabled young people could learn from each other. Understanding individual needs and respecting each young person’s

uniqueness was strongly advocated by all parents.

Culture and religion

South Asian parents of young people with a learning disability voiced concerns about the specific barriers relating to their culture and religion. The main issues were in relation to contact sports, such as football and swimming classes. These issues were relevant to young women, based on religious beliefs with regards to modesty. Although many swimming pools in Bradford offered women-only swimming, problems also arose when mothers had to take their sons swimming.

“They are not inclusive. They say this but they are not. I can’t blame the youth centres as well as they are not trained to deal with autistic children. They can’t understand him, how these children work. They need extra support, like at school they have one to one support.”
Mother

“There need to be more meetings about young people with special needs. There needs to be more education and awareness about their needs.”
Father

“I have always wanted to take him swimming. Because of our Asian culture I can’t go in the pool with my son and he wasn’t allowed to go because he is quite tall for his age. We tried going to ****pool but I can’t go there because there are fathers in the pool with their children.”
Mother

Parents also preferred female staff for their daughters. Recreational events or outings at which alcohol was served were also considered taboo by Muslim parents. However, parents were clear that it was not that important to have staff from South Asian communities for the young people as long as sensitivity to cultural and religious needs were considered. Cultural issues also included promoting pastimes specific to Asian cultures, for example Asian music. Some parents also commented on their culture, suggesting that some parents in their community did not actively question educational establishments or other organisations unless there was a problem. It was also suggested that language barriers and lack of confidence acted as a barrier in seeking information. An individual who could go into the community to see families or answer questions face to face was considered a way of improving information dissemination. Parents also felt that this form of approach would be helpful in building confidence in services and links with the community.

“She (referring to another mother who didn’t speak English) doesn’t think that there are those kinds of services out there, you know, for special needs. She thinks there is school and that is it. I don’t think she knows there are any and if there are she needs to be sent information. Because of the cultural barriers she would prefer single sex.”

“Families don’t question school. In Asian communities parents only respond if the child is playing up.”
Mother

“I am worried about safety for other people. She only goes to me when she lashes out. Can anyone else cope with her aggression?”

Mother

“Someone has to stay with the child and watch them if the child is unaware of danger or if he doesn’t know the way to go.”

Mother

“I would like my daughter to be more independent but I worry about her safety.”

Safety concerns and support

Parents expressed many concerns about the vulnerability of young people and general safety issues. This included travelling independently because they worried about bullying on public transport. The young people’s behaviour towards others, including aggressive behaviour or inappropriate behaviour, was also a cause for concern for some parents. The main concern was about the reaction of the public to the young person and their ability to respond in such situations. The dilemma of wanting independence for their children but worrying about their safety was also very evident.

The majority of parents highlighted the need for individual support. They also referred to the young person’s lack of confidence in attending an activity without adequate support. It was suggested that it may be helpful for siblings to be allowed to escort the young person to a leisure activity and to continue doing so until the young person feels more confident. Supporting the young person in understanding money and change was an additional concern for many parents.

Transport and cost of activity

Lack of transport was a major concern for most parents. Although some parents had their own transport, other parental commitments sometimes interfered with the schedule of the activities. Many of the activities were scheduled some distance away from home which hindered access. Parents were keen to have greater

involvement in local activities in which the entire family could be involved. The expense of the activities was an issue for some parents, particularly for single parents and low-income families. Some summer schemes also charged for transport, which was difficult for some of these families to afford. Safety issues around independent travel, particularly in the evening when activities were usually run, were also a concern for parents. The young person's lack of confidence to travel independently on public transport was also discussed (see previous section).

“The taxis are too expensive and my son doesn't like the bus. The family fund used to provide a car and the tax was taken out of the benefit. Transport is a big problem after 5pm to get to leisure activities as the bus service is not as frequent.”

Father

“My son has had transport training but he refused to go after the support was taken away. We were happy with him to go on his own.”

Father

Parents suggested ways of minimising transport problems. This included parents in the community coming together to share transport of the young people. This would only work, however, if the young people were accessing the same activity. Parents

also expressed the need for local community- based leisure provision in which family members could also participate with the young people. This would also minimise transportation problems. Parents also expressed willingness to contribute to transport costs if leisure providers were also able to supplement the remainder of the cost.

Parents reported positive benefits from their involvement in focus groups. They felt it provided the opportunity to meet parents in similar situations, to learn from them and to share common experiences. They also found it a valuable mechanism for finding out information. Parents suggested that the formation of a South Asian parent group would be beneficial to them.

Table 4: barriers to leisure identified by young people and carers

Barriers	Young people	Parents
Support	✓	✓
Transport	✓	✓
Money	✓	✓
Culture and religion	✓	✓
Safety and lack of confidence	✓	✓
Staff awareness		✓
Young person's behaviour		✓



Sl. No.	Name	Roll No.	Grade	Section
1	Abdullah	101	10	A
2	Abdullah	102	10	A
3	Abdullah	103	10	A
4	Abdullah	104	10	A
5	Abdullah	105	10	A
6	Abdullah	106	10	A
7	Abdullah	107	10	A
8	Abdullah	108	10	A
9	Abdullah	109	10	A
10	Abdullah	110	10	A
11	Abdullah	111	10	A
12	Abdullah	112	10	A
13	Abdullah	113	10	A
14	Abdullah	114	10	A
15	Abdullah	115	10	A
16	Abdullah	116	10	A
17	Abdullah	117	10	A
18	Abdullah	118	10	A
19	Abdullah	119	10	A
20	Abdullah	120	10	A

Part 2: meetings between service providers/young people and families

A key aim of this project was to facilitate a dialogue between the young co-researchers, their parents and leisure service providers/commissioners in Bradford so that the latter could be better informed about the barriers to leisure that South Asian families face and, therefore, be better placed to make adaptations to ensure young South Asian people are included. This was conducted over a period of eight months.

During this period several activities were happening in parallel.

- Regular meetings with the co-researchers to inform them of the process and outcomes of organising the meetings with service providers.
- Preparing the co-researchers for meetings with service providers. This was conducted by the research assistant with the co-researchers. The format used was informal discussion groups to build confidence by exploring and role playing the type of questions they would ask and answer, and exploring the areas they would address with service providers.
- Regular telephone contact with young people and carers in relation to the organisation of meetings and general feedback about the progress in relation to dates and venue and support for attending the meetings.

- Meeting with a number of service providers/contacts to build valuable links with leisure providers and other relevant agencies in Bradford. The research assistant (NP), met with various professionals to raise awareness about the project and to gather information about provision in Bradford. This process provided links to various organisations and provided the opportunity for information sharing and networking. It was an ongoing challenge to ascertain the appropriate individuals for involvement in the service provider focus group. Therefore this process was very time-consuming and eventually nine representatives from various organisations agreed to participate in the focus groups (see list of organisations represented below).

Culture, Sport and Leisure, Bradford Council
Transport and Mobility Planning, Bradford Council
Children and Young People's Partnership, Bradford Social Services
Learning Disability Partnership Board, Social Services
Policy Department, Bradford Council
Federation of Disability Sports
Transport, Social Services
Travel Training Unit, Bradford College
Bradford Youth Service

The purpose of the focus groups was to facilitate discussion with young people, parents and providers. The meetings provided a forum for consultation with the aim of addressing the issues highlighted by young people and parents and carers in their focus groups. It was envisaged that the service providers would take these issues forward as guidance in the planning and development of their services. All the meetings had a set format, which started with lunch and then a discussion. Each meeting lasted about one and a half hours. The final meeting with service providers, young people and parents had a different format. As it was during the Ramadan fasting month, we had the meeting first and then lunch so that young people and parents could leave soon after the meeting.

First meeting

Aim and purpose

- To introduce co-researchers and service providers to each other.
- To familiarise co-researchers with the process of conducting meetings.

What was the agenda?

- Warm up exercises and presentation of co-researcher's training course.

Who attended?

- Four co-researchers
- Five service providers
- Research staff

Key discussion points and action plans

A general discussion about the project took place initially. As this was the first introductory meeting, participants discussed what they expected and hoped would result from involving service providers.

Four of the seven co-researchers provided a PowerPoint presentation about their training. This meeting provided the opportunity for the young people to get to know the service providers. The young people conducted a few warm-up exercises before proceeding with their presentation. The presentation lasted for about 30 minutes and provided information about their training and what they gained from it. After the presentation the service providers asked about the type and range of leisure activities that they like to do and also talked about some of the activities that they are currently engaged in.

Action: to discuss findings from the focus group discussions held with young people with service providers at the next meeting.

Second meeting

Aim and purpose

- To present findings of young people's focus group discussions to service providers.

What was the agenda?

- The presentation of young people's views was the main item, followed by questions

from the co-researchers and a discussion of the issues raised in the presentation.

Who attended?

- Six co-researchers
- Seven service providers
- Research staff

Key discussion points and action plans

The co-researchers presented the findings of their work with the young people's focus groups. This was done using a PowerPoint presentation with support and facilitation by the research assistant.

The co-researchers asked service providers some key questions at this meeting.

- How can you change things?
- How can we become involved in planning and consultation as a reference group for service planning?
- How do parents and carers become involved in planning and consultation as a reference group?

Service providers responded to these questions by giving the young people options of how to get involved. The young people were informed about a mobility planning meeting, which would focus on transport issues. They were also informed about the Learning Disability Partnership board and sub-groups, which address various issues of importance to people with a learning disability and their families. Travel training was also identified as an option for gaining independence in transport usage.

Co-researchers response:

- Transport may be a problem in getting to places.
- As a group of individuals the role is trying to become more independent. There was only one member of the group who could travel independently.
- If an independent traveller was to assist supporting someone who was not an independent traveller, would they be paid?

Service providers' response:

- It may be possible for a group of two people or more. Competent travellers need to think of strategies on how they can help others become more independent.
- The answer was that at present no funding is available, but this needed to be pursued with service managers/ commissioners and put forward in future plans as part of the assessment of the needs of young people trying to become independent.
- Possibilities include:
 - travel training
 - writing guidelines on using transport
 - being part of reference group
 - health and safety.



Key discussion points and action plans

- Communication is key for the providers to effectively work with young people.
- Family networks are very important.
- Barriers to transport – why are they there and how can we break them down?
- Information dissemination in Bradford could be improved, especially in hard-to-reach areas.
- Parents should be invited to meetings to ensure greater representation.
- Partnership among children and young people is crucial.
- It was pointed out that parents can support each other and at times take over some of the organising of events and transport, and so on. This has happened successfully elsewhere.

- Councils are there to work with the community to ensure that young people have a voice and this is fed back to the councillors for action.

Third meeting

Aim and purpose

- To consult with parents about issues raised in focus groups.

What was the agenda?

- General questions posed to service providers and discussion with parents about issues raised in the focus groups.

Who attended?

- Three co-researchers
- Two parents
- Seven service providers
- Research staff



Key discussion points and action plans

The main purpose of this meeting was to facilitate discussion between parents and service providers, with representation from the co-researchers. The issues from parent's focus group discussions were summarised for this meeting. Unfortunately only two parents were present, which made representation of different views limited.

Two key questions explored with service providers in this meeting were based on the feedback from parents' focus groups. These were:

- the service providers' knowledge of the needs of young people with a learning disability from South Asian communities
- the ways in which services may be adapted accordingly.

There was a general discussion about work practice. However, specific agencies were concerned about specific issues. For example, the Youth Service representative felt it was important to find out why families and disabled young people have difficulty accessing the service. They have an understanding of how South Asian communities work but need more assistance with working with individuals with a learning disability. The Bradford Council representatives were keen to address the issues raised in disability equality legislation and to meet the needs of people with disabilities.

Travel training and the best way of getting information into the communities, was discussed with parents. Other issues about getting out into the community and building trust with families were discussed. Making phone calls and following up with home visits was discussed as vital to building relationships with families. This is the approach used by a local voluntary organisation that many providers rely on to make contacts with South Asian families. This practice should be implemented by all organisations working with young people with disabilities and their families. It was decided that a greater representation of parents would be more useful for the next meeting.

Participants also decided that an action plan would be drawn up to specifically address issues and to be circulated to all service providers (see action plan in the appendices).

Fourth meeting

Aim and purpose

- To generate discussion and agreement of a draft action plan.

What was the agenda?

- To go through the draft action plan developed by the research team and identify the service providers' action points.

Who attended?

- Two co-researchers
- Six carers attended
- Two service providers
- Research staff

Key discussion points and action plans

This meeting was scheduled for parents and service providers, with representation from the co-researchers. A draft action plan was produced for discussion and input from young people, parents and service providers. This draft action plan was emailed to all the service representatives before the meetings. The planned discussion on the action plan proved difficult as there were only two service providers at this meeting. As a result, the focus of the meeting centred on travel training. One family in particular was able to share positive experiences of this process. Many parents wish for independence for their children but are very concerned about independent travel due to safety concerns. However parents were willing to find out more and this was subsequently arranged with the travel training representative at a later date. Parents also raised the issue of a lack of support and networking among the families with a son/daughter with a learning disability. Parents were interested in being involved in a parent group as they found the meetings and information-sharing helpful. The co-researchers also felt that other young people with a learning disability

would benefit from an advocacy group for South Asian young people.

- Discussion of parental concerns took place and the action plan could not be directly addressed as there were only few service providers.
- Parents expressed an interest in forming a parent's support group that could provide a forum for South Asian parents and carers to discuss their concerns and also to identify the best ways of getting the required services for their son or daughter.
- The young people also expressed an interest in forming a South Asian advocacy group.
- Participants scheduled a final meeting to finalise the proposed action plan with service providers.

Fifth meeting

Aim and purpose

- To discuss the proposed action plan and to identify key providers responsible for action.

What was the agenda?

- Draft action plan
- Future directions

Who attended?

- Three co-researchers
- Eight carers
- Seven service providers
- Research staff

Key discussion points and action plans

The meeting commenced with gratitude being paid to all involved in the process. The proposed action plan (see appendix 3) was discussed with each provider with the intention of individuals taking responsibility for a role that their organisation would be able to fulfil. Parents also pointed out the need to get information out to families who have not been involved in this project.

- The travel unit representative discussed the service they were able to offer and proposed three possible ways of taking this forward. These were:
 - 1) one-to-one referrals
 - 2) assistance in getting to a leisure activity as a group
 - 3) identifying a buddy group.
- The Department of Culture, Tourism and Sport at the Bradford Metropolitan Council committed to improving the lack of provision for over 16 year olds by setting up activities that young people would like to do and also by exploring the provision of community-based activities. They

intend to build on the findings of the Aawaaz project and offer more activities. They will also incorporate findings into their strategic plan for long-term improvement of services.

- Provision of information provoked a lengthy discussion because each organisation has this responsibility. It is important to get information into communities through a number of channels, which will include the various temples, mosques and gurudwaras. It is also important to improve the quality of information to highlight the type and range of organisations, opportunities or other possible contacts. The Learning Disability Partnership Board is currently producing a directory that will include all services aimed at people with a learning disability. Information will be sent to all families involved in the research. A training programme for parents to help them be involved in meetings and influence policy and practice is also being offered in early 2008. Information about this course has been sent to families.
- Issues about raising awareness will be addressed by the council and taken forward to the equality division. Issues around culture and religion will also be taken on board. Staff within the council will be targeted in terms of awareness training around disability, culture and religion. Families also need to be involved in this awareness-raising process.

- The Federation of Disability Sports will be providing a further training course to the Aawaaz co-researchers in order to sustain this group. This will focus on empowering the young people and providing skills to organise sport and leisure activities. It is anticipated that at the end of this course the co-researchers will be able to maintain their own group and organise activities of their choice.

With the consent of young people and parents, the research team will pass on contact details and relevant information to providers to take these issues forward.

Feedback from the co-researchers

The co-researchers were integral players in this research process. They not only represented other young people with a learning disability but were crucial to the research process. People with a learning disability are experts in their own lives and have a right to be consulted. Furthermore involvement with people with a learning disability in research reinforces the quality and relevance of the research.

The co-researchers reported many benefits from being involved in the research process. They were able to foster friendships with each other and meet a variety of people. They learned and built on a variety of new skills. Their opinions were also valued and listened to. It was acknowledged by the co-researchers that they grew in confidence

and self-importance. This was also observed by the research staff and service providers who attended the meetings.

“It was good being a co-researcher. I met new people and I learned how to present to a group of people. That felt good. I enjoyed meeting service providers.”

Hammad

“The training was ok. I liked the games we played. I felt a bit nervous meeting with people but it got better. I became more confident talking to more people. I liked meeting with the girls who could not speak and helping them when we did the focus groups. We worked hard. I also liked going back to Bradford College and seeing my old tutors.”

Fozia

“It is important to work. I liked taking photographs in the research. I also liked preparing the slides for the meetings. I enjoyed meeting the other young people and I liked the activities we did in training. I liked going to meetings too!”

Natasha

“I liked being involved in the research although sometimes the talking was too long. I liked talking, dancing and the food. I also like the people but Shabab gives me a headache!”

Israr

“I liked to talk to people in the research. I liked going to Bradford College and Haycliffe to see my mates again and my old teachers. I liked seeing other researchers, it was fun. I liked coming to the meetings too.”

Shabab

“I liked meeting with the other co-researchers. I got nervous at big meetings so I didn’t go. I liked going to schools and meeting the young people. I enjoyed the activities in training.”

Ausma

“I really liked meeting with the people and seeing other people. I enjoyed all the meetings and the food. I enjoyed going to schools and asking them about sport and leisure and what they like to do. I liked the staff in school. I am looking forward to doing more training. I learned a lot of new things in this project.”

Mohammed

The success of this project is the involvement of young people. The young people felt greatly valued for their contribution and also reported to be more confident in dealing with service providers in the future.





4 Discussion

The aim of this project was to involve young people with a learning disability from South Asian communities in consulting with service providers to shape and develop appropriate and sustainable leisure opportunities. The emphasis was not to directly enquire about the barriers in accessing leisure services, as this has been already identified through other work in Bradford (Raghavan et al, 2006) and also by other researchers (Buttimer & Tierney, 2005; Beart et al, 2001).

The focus of this project was to enable young people to explore the kind of leisure activities that they wish to pursue and to look at ways to increase their access. The young people's views were subsequently discussed with service providers with the intention of planning more accessible leisure services. In doing so, this project has also trained a core group of young people from South Asian communities as co-researchers and allowed them to articulate their wishes and concerns to service providers.

The 'Valuing People' white paper (DoH, 2001) indicates the need for support among children and young people with a learning disability in terms of leisure activities. 'Valuing People' states that "People with a learning disability often do not take part in ordinary leisure activities. Leisure is rarely built into individual and community care plans. It tends to be seen as an optional extra, generally coming well down the list of agencies' priorities when decisions are being made about resources" (7.37 p.80).

We often pay lip service to the need for leisure activities for people with a learning disability in promoting health and wellbeing. Leisure involves having freedom of choice, a wide range of leisure options, and activities that include physical, cultural and social aspects (Hogg, 1995). Participation in leisure pursuits is crucial for building confidence, self-esteem and the general acquisition of skills that promote interaction and participation.

A number of major issues were raised by the young people and parents in the focus groups. These issues were also discussed with leisure providers with a view to improving on these areas and finding solutions. Many of these issues have been reported in the literature and were already known to providers. However the significance was to engage providers in discussion with young people and parents, with the view to setting precedence for ongoing consultation. These main themes are discussed in the following sections.

Lack of information and leisure provision

Many of the parents for whom English was not the first language, struggled with obtaining information about activities and did not have the confidence to seek out information due to language barriers. Parents reported a lack of information about leisure opportunities. They suggested that a central information office (a main point for contact) with the provision of

knowledgeable staff to answer questions would be helpful. Sending information out through the schools and using local community radio stations to disseminate information was also suggested.

Service providers acknowledged that this was an area that needed to be improved and spoke at length about getting information into local communities via mosques, temples and gurudwaras. The Learning Disability Partnership Board was also in the process of formulating a database in order to provide information to families caring for a person with a learning disability. However it appears more attention needs to be given to the provision of available staff and interpreters who may be able to answer questions parents may have. Often parents have general concerns and questions about services for people with a learning disability and would welcome such advice.

Previous research has also suggested that information is often inaccessible and minority ethnic carers are usually poorly informed about services. The needs of service users are not met as they tend to be excluded on the basis of language issues (Chamba & Ahmad, 2000).

Parents reported that provision of leisure activities and clubs for young people over age 16 was lacking. The young people are still very much dependent on parents and professionals in late adolescence and many

parents feel at a loss at this stage. As found in previous work on transition from school to adult services (See Heslop et al, 2002), there appears to be a gap in provision. In fact previous research stresses that young people's feelings about friendships, leisure and social life are not given sufficient attention in transition planning (Heslop et al., 2002). Research has continually stressed the importance of leisure at the transition phase and hence greater attention needs to be paid to providing activities to young people post age 16.

Disability awareness

Parents reported the need for staff training around disability issues and raising public awareness. Providing opportunities for all young people (with and without disabilities) to socialise was also suggested as it is important in building public awareness and fostering greater understanding of disability.

The Discrimination Disability Act 2005 stipulates that service providers only need to make changes that are reasonable. Simple changes to layout, improved signs and information and staff training may improve accessibility for disabled customers. However, accessibility for young people with a learning disability entails more than this and can often be more complex due to the nature of a learning disability. Again, cultural factors play an important role in this process because of the belief systems and concepts of disability held by the families. Local government agencies and volunteer

organisations should endeavour to collaborate in raising public awareness of the issues faced by young people with a learning disability and their families. Attitudes towards disability can often be negative and often stem from ignorance. Training in techniques to make leisure activities more accessible to young people with severe disabilities is also imperative (see Zijlstra & Vlaskamp, 2005). Consultation with young people about making leisure facilities more accessible is vital in making inclusion a reality for people with a learning disability.

The Youth Service has run a few events to facilitate this interaction between young people and it is hoped that such practice will continue. Bradford Council has been working towards improving access to facilities for people with disabilities and has set up a Disability Discrimination Act group. Discussion with providers have also led to a commitment to take issues raised by young people and parents forward to the equality division.

Culture and religion

Parents reported specific issues that could affect leisure access and usage. Efforts to meet these cultural needs were being addressed in Bradford, for example the provision of female-only swimming classes.

Parents were satisfied with leisure activities granted they were culturally appropriate and met the young person's needs. However, they felt assuring cultural

appropriateness should go beyond providing an accessible service.

Staff awareness and understanding of working within a multicultural society warrants further attention. This understanding may relate to deeper cultural understandings. For example, staff may define independence in terms of a construct of individuality. However, Atkin & Hussain (2003) suggest that independence and autonomy are social constructs, which may have different meanings among different ethnic groups.

For South Asian families the significance of family may be more important, thus achieving 'interdependence' may be more appropriate. As family orientations greatly affect young people's outcomes, and may restrict their ability to become independent (Bignall & Butt, 2000), the concept of 'interdependence' may be a basis for supporting young people in the community. It is also crucial for professionals to have knowledge of cultural systems in order to build links into community networks. Family support can both enable and restrict independence (Chahal & Ullah, 2004).

It is important to acknowledge how individuals differ from one another in South Asian communities, in terms of nationality and religion, and to recognise that achieving independence for the young person may have a different meaning for these families.

This will enable services to understand the cultural and religious needs of the young person and their families in a person-centred manner rather than making false assumptions based on the collective needs of South Asian communities.

Staff should also be aware of their own value-based judgements and take into consideration carers' concerns, which may be influenced by cultural and religious beliefs. Harry et al (1999) suggest that professionals working with minority ethnic families adapt the cultural reciprocity process. They propose that professionals engage in a self-reflective process in identifying both their own as well as the family's cultural norms. Cultural reciprocity refers to the efforts of staff working with families and children to understand families' cultural beliefs and to use this understanding to meet their needs.

There also appeared to be a dependency on South Asian voluntary organisations, by mainstream providers, to do outreach work with these communities. Reaching perceived 'hard-to-reach groups' can only be accomplished through active involvement and engagement with these local communities. This will help to break down barriers and to dispel myths held about these various minority groups.

In meetings with service providers the importance of conducting home visits and using an interpreter when necessary, was

discussed. This may help to build trust and forge stronger relationships between professional and families. As parents suggested, it is important for them to meet professionals face to face so that the opportunity to ask questions is presented. It also helps to build confidence in the service and allows parents to feel more assured that the young person will be adequately supervised and supported.

Safety concerns, support and transport

Individual support, to assist the young person in leisure pursuits, was requested by young people and parents. Research has continually identified that carers require a key worker or liaison worker to help them access services (Liabo et al, 2001). As Raghavan et al (2005) found, using a liaison worker model helped Pakistani and Bangladeshi families access services better than those who did not have a liaison worker. It is also important to have enablers or support workers from the same ethnic community who may be better equipped to break down cultural and language barriers.

Anxiety about safety and risk-taking was a common dilemma as parents understood the importance of letting their child become independent but felt uncertain about the young person's ability to participate in an activity or whether it was safe. In this way, services sometimes perceived parents as a barrier to their child accessing various activities.

Young people were also aware that parental concerns hindered access to activities that their non-disabled peers were involved in. Parental concerns about bullying and general safety sometimes made it difficult for parents to let go and allow the young person to achieve greater independence, for example, independent travel. Consequently, travel training for young people was discussed at great length and a separate meeting was held to inform parents about the process. It was acknowledged that many parents were reluctant to allow the young person to participate because of their own fears and anxieties. This was perhaps one of the areas that was most challenging and requires further attention and dialogue in order to work through the anxieties expressed by parents.

The building of trusting relationships with professionals may help to alleviate some of these parental concerns. McConkey & Smyth (2003) propose a model to minimise risk by adjusting factors that contribute to risk, by working in partnership with others involved with the young person and by increasing the competence of the young person. The authors suggest the model may also support parents to appreciate the young person's aspirations more and focus less on their parental wishes.

Consultation

Involvement of people with a learning disability in research that concerns them is vital. Their personal accounts may guide the way in which services adapt to better meet their needs.

Traditional research methods have discriminated against people with a learning disability; their views have seldom been sought and often others have been consulted on their behalf (Ramcharan and Grant, 1994; Booth, 1996). Therefore, engagement and consultation with service providers was a key theme of this project. The purpose was to provide the means of getting the views of young people and their families heard. As this project was only short term it was not anticipated that leisure services would dramatically change. It was accepted that this would take time.

However, it was envisaged that lessons learned from this process could be taken forward in the future planning of leisure services. It was also anticipated that valuable links would be forged between the service users and providers. The impetus behind this project was facilitating this rapport; however, one of the major obstacles was gathering all relevant individuals at meetings. Individual schedules and other commitments sometimes made it difficult to schedule meetings where everyone could be present. This included young people, parents and most importantly service providers and

commissioners. The timescale of the project also limited the number of meetings that could be held in a short period.

Consultation with young people and parents is not a prescribed and straightforward process. There were, however, specific elements that were crucial to the process. Before undertaking the consultation, it was first important to be clear about the purpose and goals of the research so that expectations were not raised. It was made explicit to young people and parents that the research was mainly about consultation and that change in services would take a longer time to materialise. However it was also anticipated that young people and parents may see more immediate outcomes such as getting more information and making links with various organisations to increase access to and usage of services. It was important to do this so that young people and parents did not feel let down or disillusioned by the process. Murray (2004) provides key messages when undertaking consultation with young people and providers. She maintains that clarity of the purpose of consultation is implicit and that communication about the purpose is clear to young people.

An integral factor in working with young people was flexibility. Although the activities and questions were prepared beforehand by co-researchers and the research assistant, there was sometimes deviation from the planning when meeting with the focus group. This depended on the group's needs,

varied levels of ability and interests of the young people as well as concentration skills. This simply meant adapting different activities or using different approaches to elicit information. For example, some groups preferred to talk more while other groups were more reserved and preferred to express themselves through artistic mediums. Using various games and activities also worked better for some. The ethos was for the young people to feel comfortable and to enjoy the process. Therefore it was based on their level of comfort and need. Respecting the young people and their views was the most important consideration. Flexibility in the approach to consultation and valuing the entire process are key elements of consultation with young people (Murray, 2004). This also includes willingness and flexibility in using a variety of creative methods to elicit information from young people with a learning disability.

Improving on and adapting more creative approaches to communication with young people with a learning disability is imperative. In order to include young people who have language difficulties, ways of communicating on their terms are needed. It is important to acknowledge that even without speech one may still find other ways of communicating thoughts and ideas. Researchers have begun to use more user-friendly approaches and person-centred methods of interviewing young people with language and communication difficulties (Cameron & Murphy, 2002;

Stalker & Connors, 2003). In order to include young people with a learning disability in research, creative and individual-based approaches need to be utilised.

When undertaking research that involves consultation with young people, the young people should be actively engaged in every stage of the process. Where this is not possible, that should be made clear to the young people. Walmsley (2004) suggests the need for researchers to clarify the role of their support in the research process and to be more lucid about their input. There may also be a danger of tokenism if people with a learning disability are not having genuine or effective participation in the research (Walmsley, 1995).

Black and minority ethnic communities should have greater involvement in policy and practice development as well as in the development, management and provision of services. In addition, consultation should be with carers of people with disabilities and with the young people themselves. It seems, however, that groups that represent people with a learning disability who are from minority ethnic communities are small and under-funded (Mir and Nocon, 2002). Services should actively seek to improve cultural appropriateness so they meet the linguistic and religious needs of these young people and their families. The utilisation of professional interpreters to assist the families and service agencies should also be encouraged. This is important in getting the information out to families, and in

maintaining contact with and ensuring their involvement in subsequent planning meetings.

Fostering peer support groups for young people with a learning disability may provide positive benefits to the young person's self-esteem. This was observed with the co-researchers as their confidence grew throughout the research both in themselves individually and as a team. Parents who attended meetings also spoke of the value of getting to know other parents who had similar experiences and whom they were able to identify with. It also provided the opportunity for information sharing. The fostering of such support groups within the community may promote a stronger voice for families caring for a young person with a learning disability.

Conclusion

Young people reported a variety of factors which affected leisure involvement. The lack of useful and accessible information, transport and support all had an impact on their access to leisure. They also voiced concerns about costs and safety. Young people with a learning disability from South Asian communities have aspirations similar to peers who do not have a disability, but they have little opportunity to achieve them. The challenge is to meet the leisure needs and aspirations of the young person on a more realistic and personal basis. Further attention needs to be given to initiatives which increase the levels of friendship

activities for people with a learning disability (Emerson & McVilly, 2004).

Parents also reported specific issues such as a lack of information and adequate provision. Raising disability awareness and challenging negative attitudes to disability were also very important concerns for parents. Parents also faced dilemmas in relation to the safety and risk of young people using public transport and some leisure facilities independently people.

Many of these issues raised by parents in the Aawaaz project have also been identified in previous research with white families caring for a child with a learning disability. However there were other factors such as language barriers and cultural and religious needs, which should be considered by leisure providers in the delivery of culturally appropriate services. It is therefore important for young people and families from black and minority ethnic communities to be consulted so that their views are represented and services are able to meet a variety of needs in the community.

The policy guidelines from the Department of Health detailed in 'Learning Difficulties and Ethnicity: A Framework for Action' (p.47, DoH, 2004) state that "those responsible for services for children and families with disabilities should ensure that key issues facing people from minority communities are identified and properly addressed within the services they commission and provide".

The aim of this research was to enable young people with a learning disability from South Asian communities and their families in Bradford to engage in a consultation process with the service commissioners and providers with special reference to leisure services. This engagement process enabled young people to inform service providers of their leisure interests and also to communicate ways of improving access, increasing staff sensitivity to their cultural and religious needs, and providing better information about leisure services/ opportunities that is easily available and accessible to young people and their carers.



5 Recommendations

There are a number of recommendations that we put forward for service commissioners and providers from this project.

Involvement and participation

- Involvement of young people should progress beyond the tokenistic representation of readily available people with a learning disability. This would allow for wider representation of views from people with a learning disability from different ethnic communities.
- Peer support groups will provide young people with a learning disability from South Asian communities the opportunity to form friendships and build support networks. This will provide the young people with a united voice in shaping the leisure services.
- Young people with high support needs from South Asian communities require the opportunity to engage in leisure activities offered by mainstream providers. These young people require additional support. Therefore, services should focus on better utilisation of resources. It is also important for young people to have access to mainstream activities, because being involved purely in severe and complex learning disability groups will only continue to hinder social inclusion.

Engagement with local communities

- Greater participation in local communities should be facilitated to build stable networks and to promote social inclusion. Resources should also be put into building more community-based activities. This might ease the transport problems and increase access.
- Engagement with young people and carers from South Asian communities is vital to fostering links with this community. Reaching perceived 'hard-to-reach-groups' can only be accomplished through active involvement and engagement with these local communities. This will help to break down barriers and to dispel myths held about these various minority groups.
- Conducting home visits and using interpreters when necessary may help to forge stronger relationships between professionals and families. Parents and other family carers should have the opportunity to meet service providers face to face so that they can directly engage with them in relation to their concerns and opinions. This will help to build confidence in the service and to feel reassured that the young person will be adequately supported and supervised.
- Cultural diversity and cultural competency training should be provided to service providers, service commissioners and support workers to enhance their understanding of the religious and cultural needs of the young South Asian

people and their family carers. Staff training should aim to increase awareness of how individuals differ from one another within ethnic and cultural groups. Awareness and understanding of cultural myths and assumptions, and their influence in the negative shaping of attitudes and behaviour, should be promoted.

- Young people and their families require help and support with transport.

Consultation

- Services need to regularly engage in consultation with young people from South Asian communities and families when planning and shaping leisure services. Services need to show their commitment and willingness to engage with the young people and families by establishing flexible and creative communication networks with South Asian communities.
- Services need to invest in fostering and facilitating community links, and in building trust with the local South Asian communities, which will help to facilitate the growth of stronger relationships and positive partnership working.
- The formation of a South Asian family support group/network has been suggested by parents. This will help to strengthen wider contacts among the families and young people. This will also act as a forum for information exchanges about leisure services.

Inclusive services

- Mainstream leisure services should be more inclusive of young people with a learning disability. This may include providing disability training to staff and raising awareness. Training in techniques to make leisure activities more accessible to young people with severe disabilities is also imperative.

Information and communication

- Information about services in accessible language and pictorial format should also be provided to the young people so that they are able to make informed choices. Information may also be provided in the form of videos, DVDs and accessible websites.
- Information should not just be provided in leaflets as some of the Asian languages spoken in Bradford do not have a written format (for example Mirpuri (Punjabi) and Sylehti (Bengali)). Providing information on Asian radio stations and also through local places of religious worship such as temples, mosques and gurudwaras and churches may reach out to more people.
- The utilisation of professional interpreters to assist the families from South Asian communities to communicate appropriately with service agencies should be standard practice for services operating in a multicultural society.

References

- Atkin, K., and Hussain, Y. (2003) Disability and ethnicity: How young Asian disabled people make sense of their lives. In: Riddell, S. and Watson, N (Eds.), 'Disability, culture and identity'. Pearson, Prentice Hill.
- Azmi, S., Hatton, C., Emerson, E. and Caine, A. (1997) Listening to adolescents and adults with intellectual disabilities from South Asian communities. 'Journal of Applied Research in Intellectual Disability', 10, 3, 250-263.
- Beart, S., Hawkins, D., Kroese, B.S., Smithson, P., and Tolosa, I. (2001). Barriers to accessing leisure opportunities for people with learning disabilities. 'British Journal of Learning Disabilities', 29, 4, 133-138.
- Beth, H., Rueda, R., and Kalyanpur, M. (1999) Cultural reciprocity in sociocultural perspective: adapting the normalization principle for family collaboration. 'Exceptional Children', 66, 1999.
- Bignall, T. and Butt., J. (2000) 'Between ambition and achievement: young black people's views and experiences of independence and independent living'. Joseph Rowntree Foundation.
- Booth, T. (1996) Sounds of silence: Narrative research with inarticulate subjects. 'Disability and Society', 11, 55-69.
- Browder, D. M. and Cooper, K.J. (1994) Inclusion of older adults with mental retardation in leisure opportunities. 'Mental Retardation', 32, 2, 91-99.
- Butt, J., and Mirza, K. (1996) 'Social care and black communities'. London, Race Equality Unit.
- Cameron, L. and Murphy, J. (2002) Enabling young people with a learning disability to make choices at a time of transition. 'British Journal of Learning Disabilities', 30, 105-112.
- Chahal, K. and Ullah, A. I. (2004) 'Experiencing ethnicity: Discrimination and service provision'. York, Joseph Rowntree Foundation.
- Chamba, R. and Ahmad, W. I. U. (2000) Language, communication and information: the needs of parents caring for a severely disabled child. 'Ethnicity, disability and chronic illness'. W. Waqar. Buckingham, Open University Press.
- Datillo, J. and Schlein, S.J. (1994) Understanding leisure services for individuals with mild mental retardation. 'Mental Retardation', 32, 1, 53-59.
- Department of Education and Skills (DfES) (2003) Every Child Matters. Nottingham, DfES.
- Department of Health (2001) 'Valuing People: A new strategy for learning disability for the 21st century'. Norwich, Stationary Office Limited.

Department of Health (2004) 'Learning Difficulties and Ethnicity: A framework for action'. London: Department of Health.

Duvdevany, I. (2002) Self-concept and adaptive behaviour of people with intellectual disability in integrated and segregated recreation activities. 'Journal of Intellectual Disability Research', 46, 5, 419-429.

Emerson, E. & McVilly, K. (2004) Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. 'Journal of Applied Research in Intellectual Disabilities', 17, 191-197.

Geishthardt, C. L., Brotherson, M. J. and Cook, C. C. (2002) Friendships of children with disabilities in the home environment. 'Education and Training in Mental Retardation and Developmental Disabilities', 37, 3, 235-257.

Gilbert, T. (2004) Involving people with learning disabilities in research: issues and possibilities. 'Health and Social Care in the Community', 12, 4, 298-308.

Heslop, P., Mallett, R., Simons, K. and Ward, L. (2002) 'Bridging the divide at transition: what happens for young people with learning difficulties and their families?' British Institute of Learning Disabilities.

HMSO (1989) 'The Childrens Act 1989'. London, Stationary Office Limited.

HMSO (1990) 'The National Health Service and Community Care Act 1990'. London, Stationary Office Limited.

HMSO (1995) 'The Disability Discrimination Act 1995'. London, The Stationary Office Limited.

HMSO (1998) 'Human Rights Act 1998'. London, The Stationary Office.

HMSO (2005) 'The Disability Discrimination Act 2005'. London, The Stationary Office.

Hussain, Y., Atkin., C. and Ahmad, W. (2002) 'South Asian disabled young people and their families'. Policy Press, Joseph Rowntree Foundation.

Lewis, A. and Porter, J. (2004) Interviewing children and young people with learning disabilities: Guidelines for researchers and multi-professional practice. 'British Journal of Learning Disabilities', 32, 4, 191-197.

Liabo, K., Newman, T., Stephens, J. and Lowe, K. (2001) 'A review of key worker systems for disabled children and the development of information guides for Parents, children and professionals'. Cardiff, Wales Office of R&D for Health and Social Care.

McConkey, R. and McGinley, P. (1990) 'Innovations in leisure and recreation for persons with a mental handicap'. Lisieux Hall, Whittle le Woods, Chorley, Brothers of Charity Services.

McConkey, R. and Smyth, M. (2003) Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences. 'Children and Society', 17, 18-31.

Mir, G. and Nocon, A. (2002) Partnerships, advocacy and independence. 'Journal of Intellectual Disabilities', 6, 2, 153-162.

Mir, G., Nocon, A., Ahmad, W. and Jones, L. (2001) 'Learning Difficulties and Ethnicity'. London, Department of Health.

Murray, P. (2002) 'Hello! Are you listening? Disabled teenagers' experience of access to inclusive leisure'. York, Joseph Rowntree Foundation.

Murray, P. (2004) 'Making connections: developing inclusive leisure in policy and practice'. York, Joseph Rowntree Foundation.

Pawson, N., Raghavan, R., Small, N., Craig, S. and Spencer, M. (2005) Social inclusion, social networks and ethnicity: the development of the Social Inclusion Interview Schedule for young people with learning disabilities. 'British Journal of Learning Disabilities', 33, 1, 15-22.

Pope, C., Ziebland, S., and Mays, N. (2000) Qualitative research in health care: Analysing qualitative data. 'British Medical Journal', 320, 114-116.

Rabiee, P., Sloper, P. and Beresford, B. (2005) Doing research with children and young people who do not use speech for communication, 'Children and Society', 19, 5, 385-96.

Raghavan, R., Waseem, F., Small, N. and Newell, R. (2005) Supporting young people with learning disabilities and mental health needs from a minority ethnic community. In: 'Making us count: Identifying and improving mental health support for young people with learning disabilities'. London, The Foundation for People with Learning Disabilities.

Ramcharan, P. and Gordon, G. (1994) Setting the agenda for empowering persons with a disadvantage within the research process. In: Rioux, M and Bach, M (Eds). 'Disability is not measles: New research paradigms in disability', Ontario, the Roeher Institute.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., and Linehan, C. (2001) Social networks of people with mental retardation in residential settings. 'Mental Retardation', 39, 201-214.

Rogers, J. (1999) Trying to get it right: Undertaking research involving people with learning difficulties. 'Disability & Society', 14, 4, 421-433.

Sigelman, C. K., Budd, E. C., Spanhel, C. L., and Schoenrock, C. J. (1981) When in doubt say yes: Acquiescence in interviews with mentally retarded persons. 'Mental Retardation', 19, 53-58.

Solish, A., Minnes, P. and Kuperschmidt, A. (2003) Integration of children with developmental disabilities in social activities. 'Journal of Developmental Disabilities', 10, 115-120.

Stalker, K. (1998) Some ethical and methodological issues in research with people with learning difficulties. 'Disability & Society', 13, 1, 5-20.

Stalker, K. and Connors, C. (2003) Communicating with disabled children. 'Adoption and Fostering', 27, 1, 26-35.

Walmsley, J. (1995) Helping ourselves. *Community Care*, 1-7, 26- 27.

Walmsley, J. (2001) Normalisation, emancipatory research and inclusive research in learning disability. 'Disability & Society', 16, 2, 187-205.

Walmsley, J. (2004) Inclusive learning disability research: the (nondisabled) researcher's role. 'British Journal of Learning Disabilities', 32, 2, 65-71.

Ward, L. and Simons, K. (1998) Practising partnership: involving people with learning difficulties in research. 'British Journal Learning Disabilities', 26, 128-131.

Williams, R. and Dattilo, J. (1997) Effects of leisure education on self-determination, social interaction, and positive affect of young adults with mental retardation. 'Therapeutic Recreation Journal', 33, 4, 244-258.

Williams, V. (1999) Researching together. 'British Journal of Learning Disabilities', 27, 48, 51.

Williams, V. and Heslop, P. (2005) Mental health support needs of people with a learning difficulty: a medical or a social model? 'Disability & Society', 20, 3, 231-245.

Zjjilstra, H. P. and Vlaskamp, C. (2005) Leisure provision for persons with profound intellectual and multiple disabilities: quality time or killing time? 'Journal of Intellectual Disability Research', 49, 6, 434-448.

Appendices

Appendix 1

Project steering group

- Andy Parkin, Early Years and Childcare
- David Bird, Mencap
- Chris Russell, The Inclusion Project
- Tariq Ahmed, Bradnet
- Emma Gee and Kay Wells, Mind the Gap
- David Benn, Barnardos
- Vicky Donnelly, community team for learning disabilities (Bradford District Care Trust)
- George Dean, equality and diversity manager, (Bradford District Care Trust)

Appendix 2

Members of service provider focus group

- Steve Grisag, development officer, Bradford Council
- Taj Butt, Culture, Sport and Leisure
- Carolyn Hargreaves, Children and Young People's Partnership, Bradford Social Services
- Ian Brooke-Mawson, Learning Disability Partnership
- Darryl Smith, Policy, Bradford Council
- Tony Stones, Federation of Disability Sports
- Michelle Pickles, Transport Social Services
- Chris Walters, Travel Training Unit, Bradford College
- Paul Hamilton, Youth Service

Appendix 3

The action plan proposed and agreed with young people, families and service providers.

Issues	Objectives	Actions	Name of individual who will take action forward
Leisure activities			
<ul style="list-style-type: none"> Lack of provision for over 16. Lack of engagement with young people. Lack of stimulating activities. Limited clubs for people with a learning disability. Limited opportunity to form and sustain friendships. 	<ul style="list-style-type: none"> To improve opportunities for young people with a learning disability to access leisure. 	<ul style="list-style-type: none"> Provide community-based activities. Provide more leisure schemes and staff. Provide more inclusive mainstream activities that involve interaction with non-disabled peers. Sustain the Aawaaz group of co-researchers beyond the life-span of this project and utilise their training and personal experiences for the shaping of services. Empower young people from minority ethnic communities to enable them to express their wishes and aspirations. Foster peer support groups so as to provide young people with a learning disability the opportunity to form friendships and build support networks. 	<p>Bradford Sports Youth Service Federation of Disability Sports</p>

Issues	Objectives	Actions	Name of individual who will take action forward
Safety concerns			
<ul style="list-style-type: none"> • Bullying on public transport. • Vulnerability of the young person. • Young person's behaviour. • Some young people also have anxieties and lack of confidence. 	<ul style="list-style-type: none"> • To consider parents' and young people's feelings in order to meet their needs. • To build trust, looking at own value base and understanding those of families to meet their needs. • To work with parents, young people and providers in partnership. 	<ul style="list-style-type: none"> • Travel training – though parents still have concerns which need to be further considered. • Contact and liaise with families via home visits – this will help to build trust. • Ensure parents and young people feel safe and confident. 	Travel Training Unit
Transport			
<ul style="list-style-type: none"> • Expense was an issue as some summer schemes charge for transport. • Other parental commitments. • Safety issues and young person's lack of confidence to travel independently were also discussed. 	<ul style="list-style-type: none"> • To make transport more available to young people. • To find ways of minimising transport costs for parents. 	<ul style="list-style-type: none"> • Travel training, daytime travel, or a buddy system. But need to build up confidence of parents and young people. • Local community-based activities would make transport less problematic. • Providing transport to activities. 	Travel Training Unit

Issues	Objectives	Actions	Name of individual who will take action forward
Support			
<ul style="list-style-type: none"> • Need for one-to-one support. • Lack of confidence in the young person. • Support with understanding money. 	<ul style="list-style-type: none"> • To have more one-to-one support or group support. 	<ul style="list-style-type: none"> • Provide a key worker to work with the young person, supporting their needs, and building confidence. 	Travel Training Unit
Culture and religion			
<ul style="list-style-type: none"> • Specific issues are important to parents but they are happy for young people to be involved as long as they are respected. 	<ul style="list-style-type: none"> • To bring about an improved understanding of cultural diversity, with the focus being on the understanding of the religious and cultural needs of the young person and their family carers. This should include an awareness of how individuals differ from one another within ethnic and cultural groups. • To promote awareness of cultural myths and assumptions. 	<ul style="list-style-type: none"> • Consultation with parents and young people – this should lead to a greater understanding and improved ability to meet the needs of this group. This may include involvement in various sub-groups or committees. • Consulting parents and young people – this should help to shape services to better meet their needs. 	Bradford Council Equality Division Learning Disability Partnership Board, Bradford

Issues	Objectives	Actions	Name of individual who will take action forward
Lack of information			
<ul style="list-style-type: none"> A lack of information about leisure provision was reported. 	<ul style="list-style-type: none"> To improve information sharing and to provide accessible information to parents and young people. 	<ul style="list-style-type: none"> Provide information via the radio. Establish a central office with staff on hand to provide information about all disability issues and provide support and to explain options. Provide home visits to families. Provide information at local community centres and places of worship. 	<p>Learning Disability Partnership Board, Bradford</p> <p>Bradford Council</p> <p>Youth Service</p>
Staff lack of awareness			
<ul style="list-style-type: none"> It was reported that staff lack awareness of disability issues. 	<ul style="list-style-type: none"> To improve disability awareness training for staff as there is poor awareness of these issues. To challenge negative attitudes towards people with disabilities. 	<ul style="list-style-type: none"> Provide disability awareness training is important for staff working in mainstream leisure provision as they often have limited contact with people with disabilities and may not have the confidence to support the young people appropriately. The co-researchers could be involved in raising the profile of young people with a learning disability, particularly from South Asian communities. 	<p>Bradford Council Equality Division</p> <p>Bradford Sports</p> <p>Learning Disability Partnership Board, Bradford</p>

Notes

Notes



Mencap

123 Golden Lane

London EC1Y 0RT

Telephone: 020 7454 0454

Fax: 020 7608 3254

Email: help@mencap.org.uk

www.mencap.org.uk

Learning Disability Helpline

0808 808 1111