Proud2B: An evaluation of outcomes for adults with a learning disability from minority groups in Hampshire participating in a club celebrating and exploring culture

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Abstract

Social care is changing. Making choices, becoming or remaining independent, choosing your care or the right service for your needs are key elements of the new system. Expressing choices and needs related to culture can seem very intimidating if you have a minority culture, even more so if you have a learning disability and feel isolated living in an area where diversity is low. This report is an evaluation of the Proud2B groups, set up as a positive opportunity to encourage people with a learning disability from black and minority ethnic backgrounds to develop self-confidence and self-advocacy skills in order to express their needs and wishes. The aims of the groups are to celebrate and explore members' and other cultures. Through the analysis of data from interviews, questionnaire and diaries, the research concludes that attending the Proud2B groups has had a positive effect on members' lives and identifies additional effects for supporting staff and community engagement.

Keywords: Learning disability, black and minority ethnic, culture, group-work

Introduction

Changes in social care mean that it will be increasingly important for service users to be able to express their needs to obtain the service they want. It will also be essential for providers, if they wish to remain competitive, to demonstrate how they meet those needs beyond basic care and support. Expressing needs related to a minority culture can seem very intimidating and initiatives that encourage and empower people to do so are important. There is little research about this subject and few initiatives aimed at increasing the self-advocacy skills of people with a learning disability from an ethnic minority origin. This report is an evaluation of outcomes for people with a learning disability from black and minority ethnic origin who participated in a group called Proud2B. The aim of the group was to celebrate and explore members' and other cultures to increase self-confidence and encourage the development of self-advocacy skills. The

research explored whether participants enjoyed attending the group and whether it had an effect on their lives and skills. It also constitutes a useful example of practice for all those striving to develop a more appropriate service for everyone living in their area.

Hampshire is a large and substantially rural county with relatively small and widely-dispersed ethnic minority communities (CVS, 2004, p.5). Figures from the 2001 census suggest that the ethnic minority presence in Hampshire, while still below the national average, had increased by 73% since the previous census. More recent data from local services and the voluntary sector suggest a further, accelerating growth and an increase in the diversity of origin. Ethnic minority settlement has remained dispersed although there is an historical 'pocket' of concentration in the south of the county, near Southampton, and some new patterns of concentration emerging in two areas in the north. As this is a recent development,

communities are seldom organized or represented making it difficult for providers to identify and engage with them. Another peculiarity of Hampshire is that 'travellers' are one of the larger ethnic minority groups (CVS, 2004, p.5). Finally, recent figures from Hampshire learning disability strategic commissioning team show an under-representation in support services of adults from black and minority ethnic origin (Hampshire County Council, 2009).

The North Wales Race Equality Network (undated report, p.7) identified lack of information as one of the key barriers in accessing services and support. The Network also found that rural isolation was likely to exacerbate racism and gives four reasons why this problem is often ignored:

- Denial of ethnic minority presence in rural areas;
- Colour blind approach to ethnicity, or 'we treat everyone the same' approach, which leads to people's diverse needs being ignored;
- A belief in rural areas that racist violence is an urban problem;
- A lack of effective support and consultation for ethnic minority people isolated in rural areas. (p.43)

In rural areas, where the ethnic minority population is dispersed, it is also difficult to find and receive accurate and up-to-date information; an early scoping exercise by Hampshire Ethnic Minority Learning Disability Project (EMLD) found a widespread lack of awareness of the availability of support services amongst the Black and Minority Ethnic (BME) population (EMLD, 2005). Williams *et al.* (2007) highlight the apparent lack of information and access to care for BME populations in Wales and conclude that the lack of appropriate information, language barriers, culturally-alien services and institutional discrimination are all issues mirrored by the research findings of studies conducted elsewhere in the UK. This makes

it all the more important to develop structures and activities that reduce isolation, encourage participation and empower ethnic minority people to identify their needs and gain access to the appropriate services. *Valuing People Now* emphasises the importance of including everyone in the development of strategies and services, especially in rural areas where diversity may be less visible (Department of Health, 2009, p.41).

The UK government is now committed to radical social care reforms where people's personal needs, independence, well-being and dignity are placed at the core. Hampshire County Council (HCC) has developed its own model of support to citizens in which services, whilst still important, play a secondary role to what people can do themselves with the support of families, friends and the wider community (HCC, 2008, p.92). For all in Hampshire to benefit, steps must be taken to reduce ethnic minority residents' isolation and encourage participation.

In this study, the terms 'ethnic minority' and 'minority group' are used to represent any ethnic group except White British. They might also apply to people from faith groups other than the main Christian ones. The Commission for Human Rights and Equality emphasises that it is the level of social exclusion suffered by a particular group (this could be on the grounds of ethnicity, religion, sexual orientation or other) that matters when working to ensure everyone has equal access and opportunity to be involved.

Proud2B Groups

Proud2B are two groups for people with a learning disability from ethnic and other minority backgrounds. The aims of the groups are for members to have fun, make new friends, celebrate their own culture and explore other cultures; this is then a stepping stone to develop self-esteem and pride and thus self-confidence to express

their own needs, particularly those linked to culture. The groups were set up as a positive opportunity for people who would usually be 'surrounded' by White British people and who might not feel confident or comfortable to express their own different needs, feeling as if they were in a 'fish-bowl'.

A new, positive and innovative opportunity

The Ethnic Minority Learning Disability Project was set up in 2005 by Hampshire Learning Disability Partnership Board in response to *Valuing People* (Department of Health, 2001). The aim of the project is to be a two-way link between individuals with a learning disability and families from ethnic minority groups and support services. Therefore, the project runs training sessions in the community to raise awareness of learning disability issues and of the availability of services. It also supports individuals and families to access services. Finally, it supports services with cultural awareness training and advice on specific issues. A major part of the project work is to engage with communities and specific projects, such as the Community Tree (Rawlings, 2008, p.85), provide positive and innovative ways to do this. The Proud2B groups were established with a similar purpose and represent a day-opportunity that is open to all. There is no cost involved for the individual or the family, no lengthy assessment nor referral forms to fill in and no eligibility criteria.

Rationale

The Social Care Institute for Excellence (SCIE) (2006, p.10) has denounced the widening gap between the participation of black and minority ethnic and other service user groups. It also criticizes providers who engage only with prominent figures or community leaders, rather than with potential recipients of services and their families. The Proud2B groups were set up to provide an opportunity for engagement with disabled ethnic minority individuals, rather than with prominent figures, in a community group.

In the past, debate about participation has tended to use the term 'hard-to-reach', suggesting that there is something about these individuals that prevents their engagement with services. A report by SCIE (2009, p.v) about developing inclusive participation in social care explains that 'seldom heard' is a better term as it stresses the responsibility of agencies to reach out to excluded people, ensuring that they have access to social care services and that their voices are heard. The Report also explains that getting involved includes sharing experiences with people in the same situation or enjoying oneself, i.e. having fun through shared experiences and activities (p.5). Finally, it gives an example of a mainstreaming approach to equalities (p.10) where, as in the Proud2B groups, people learn about each other's cultures through festivals and celebrations. In the new social care context, if personalisation is to bring benefits to all, the participation of 'seldom heard' individuals and groups is vital. People with a learning disability from a minority background constitute such a group and it is in that participatory spirit that the Proud2B groups were established.

Personalisation includes the recognition that every person is unique and has unique needs. Thompson (2002, p.93) argues, further, that anti-discriminatory practice must include recognising the individual, not just in the abstract, but within the concrete circumstances of her or his cultural and social context. Scourfield *et al.'s* (2005) study of cultural identity in virtually all-white communities found that diverse individual histories and family relationships interact with available minority cultural identities and local and national cultural influences. They concluded that some respondents maintain minority ethnic identities with pride and that, for others, the maintenance of a minority ethnic identity is

put under extreme pressure. For personalisation to become a reality, diversity initiatives such as the Proud2B groups are essential. Diversity is the celebration of differences between people; it goes hand in hand with equality of opportunity but is not the same. While the EMLD project contributes to equality of opportunity, the Proud2B groups help the work go further by providing opportunities for people to celebrate their 'differences'.

Organisation

Initially, interest was raised and members recruited by advertising a potential new group via the EMLD and other networks. Funding was identified and secured for two groups. It included an element covering transport, so that people from any part of Hampshire could join. It also included provision to rent venues in the community, accessible and acceptable to all.

At the first meeting, people were encouraged to think about which activity they would like to get involved in and also to draw some common rules for the group. Talking about where each person came from quickly became a firm favourite as well as looking on a large world map where the country was situated. Activities were then developed to match country of origin with other interests. The meetings take place monthly and each time there is a different theme: carnival and dance, fabric patterns, celebrations and henna tattoos, musical rhythms of the world, printing, food, going/eating out.

Membership

The groups include 11 members from 10 different ethnic origins: two are fully bilingual and use a language other than English at home, a further three know and speak the language of their country of origin but use English in their everyday lives. All speak and understand English, some members use signing (Makaton).

Research design and data collection process

The main research question was whether participation in the group had had an effect on members' lives, opportunities and skills. The primary objectives were to find out whether participants enjoyed attending the group; whether it helped them want to investigate other cultures and whether it helped them feel proud of their own. Finally, whether it gave people more self-confidence and opportunities to participate in social activities.

There has been little research on similar opportunities. Singh (2005) highlighted the importance of including heritage and cultural tradition in projects for building trust with participants and the wider community. He also concluded that sharing personal life stories in safe group settings proved highly effective in changing people's lives. Brown (2008), in a review of a similar group in Oxford, found that members were afforded an opportunity to spend time in an environment that provided culturally-appropriate support. It was set up as a self-advocacy group but became much more, encouraging members to celebrate their culture and develop confidence.

Methodology

Qualitative data was collected from three groups of respondents: participants; supporting staff; and parents/carers. Methods included:

1. Semi-structured interviews for participants, conducted in small friendship groups as many participants would have felt very intimidated one-to-one. The interview started with closed questions, based on specific activities, to make people feel comfortable by talking about something concrete. More open questions followed to capture people's views and feelings;

2. Face-to-face, semi-structured interviews with staff;

3. Postal questionnaires sent to parents with an option to use a telephone interview covering the same questions. This was done to minimise inconvenience to carers – who might prefer not to be called at home – while still being able to capture the views of those carers who did not feel comfortable with a written exercise;

4. Diaries kept of the meetings with comments and observations.

The sample included nine group participants, four paid supporting staff and one volunteer, nine families and carers. The aim was to represent the views of people involved in the group, as well as of people who might observe the effect of the group on participants outside meetings.

Validity

Because the main researcher was involved with the groups, a co-researcher (not involved with the group and unknown to the participants) was used to conduct the interviews. Accessible consent forms were produced and explained by support workers, not the researcher. Data collected was coded and analysed according to the research objectives and bias avoided by using a second coder. A high level of intercoder agreement was achieved, reinforcing the credibility of the findings.

Ethical considerations

Approval was obtained from Hampshire County Council Research Governance Board. To uphold confidentiality, neither name nor country of origin were recorded during interviews. All participants were identified in their care setting as having capacity to make a decision about participating in this research. An accessible letter and consent form were drafted and given to participants at one of the group meetings, in advance of the co-researcher's visit. This allowed supporters to explain it on a one-to-one basis according to people's needs. Two group members needed more time to think about giving their consent. The letter and the aims of the research were re-explained to them on a different day. Separate letters and consent forms were also produced for parents or carers and for staff and included pre-paid envelopes for replies.

Results and discussion

Data from interviews, diaries and questionnaires were first coded according to the primary objectives of the research and a summary of findings is presented below.

Do participants enjoy attending the group?

Analysis of the data shows that, overall, members enjoy attending the group. Enjoyment is expressed differently depending on a person's ability to verbalise. Only a few members were able to answer this question directly during the interview, partly because of their level of communication but also because the researcher asking the questions was a stranger - group members seemed very intimidated by his presence initially. Most members required considerable prompting, by the interviewer and (primarily) by the supporters, to enable them to speak at all. However, the interviewer quickly noticed that observation of facial expression particularly and body language in general would enable identification of responses. As the session progressed, group members also began to use drawing, Makaton signing, photographs and personal possessions they had brought to communicate their ideas. This allowed the interviewer to conclude that most enjoyed coming to the group. However, one member was unable to communicate, though his supporter tried a variety of activities with him. Eventually, he assisted a little with gluing items for a poster. The interviewer was unable to draw any conclusions directly from this member

although his supporter indicated that he was happy to come to the group each time it met and that he was capable of demonstrating his dislike of something. This indicates that traditional interview methods might not always be suitable for people with limited verbal communication and learning disabilities. Researchers must be prepared to use other clues, using interview questions only as a frame.

Enjoyment was also confirmed by responses from carers and from diaries. These show that appreciation was not always immediate but developed over time. For the first two meetings, there were still reports of people saying they are bored at specific activities or, on one occasion, that they do not like the venue; these no longer appear after the third session. One member is reported asking at the first meeting "why do I have to be here, I am British?" Nevertheless, she attended further meetings and, on the fourth one, introduced herself to a guest with these words: "Hi, I am …, I was born in London and my mum comes from …, I love both, what about you?" Furthermore, whereas during the first few sessions, there are occasional reports of people smiling and laughing, this progresses to becoming reports of eager anticipation and excitement: one supporter reported in the diary "she cannot wait for the next session; she has talked about it all week!" or "her dad tells me she got up at 5 a.m. this morning and was signing about today's activity". With regards to the member who did not communicate at the interview, later diary reports show him enjoying an outing, being engaged throughout and talking to a supporter using a full sentence.

Beyond answering our research question, the data also shows the importance of giving people time to develop and enjoy the group. For some, this only occurred once members became familiar with supporters and settings. It would therefore be important for a future group to run consistently over time so that people became familiar with it. Also,

new members should be given the chance to experience several meetings before being asked to decide whether they carry on coming or not.

Do participants want to investigate other cultures?

Responses to the interview questions show that the activities people preferred were looking at the world map, identifying which country people came from, as well as watching films about these countries. The diaries also show that, over time, members became more confident and interested in asking visitors about their country and culture: some asked guests questions about some aspect of their culture or religion, in one case also asking how people with a learning disability were considered.

One group has decided to try different food and restaurants as part of their meetings and is writing a local restaurant review. Originally, they had chosen to go to traditional outlets but, with encouragement, they tried other options and are even bringing in recipes from their own culture for others to try. After a trip to an exhibition about Ghana, one person commented that it was a shame they had not talked to someone from that country.

Reports from diaries show that members now expect the world map to be available at each meeting and that they will meet people from different cultures and countries. Over time, many would enquire in advance about the theme of each meeting. They developed an awareness of the importance of culture and origin and understood that this was a subject many people liked to talk about. This, in turn, gave them confidence to talk about themselves as shown in the next section.

Most supporters reported that attending the group had had an effect on their practice and one commented, "it has helped to raise my awareness of how important it is to support

people to explore their background, culture and custom, and respect differences. It is important to ensure people have opportunities to do this". One day-service attended by a group member felt inspired by the experience and is now running its own cultural diversity group. The service reported that diversity had become much more a part of their work and that even people in a 'nature group' were asking questions about where different plants grew and were pleased to find out when it was a country someone at the centre came from.

Are participants showing pride in their own culture?

The interviewer noted that activities that encouraged identification with the country of origin appeared to be of greatest importance to individual members. His conclusion from the interviews was that the group related to issues that were important to members and provided a 'me-time' that was not usually available in traditional services. The diaries consistently contain reports of members spontaneously asking others where they came from and talking about their own origins. One member, on returning to his day-service went round telling everyone where he came from and the centre manager described him as "beaming". On an outing, this same person engaged in conversation with a shopkeeper about countries of origin and explained where he, as well as other group members, came from. This person does not usually communicate easily and has a speech impediment when pressed.

The group has also provided members with opportunities to use their first language. Brown (2008) found that this had been very welcome by group members and allowed "true feelings and expression to show" (p.19). At Proud2B meetings, guests were invited who spoke the languages of the members. Facial expression of contentment was clearly evident when conversing in first language. One of the supporters reported that he felt much more proud of his own background and said, "I feel privileged to be different". This shows that such groups, set up primarily for service users, may also benefit staff and demonstrate commitment to equality and diversity, as well as promote harmony within the workplace.

Effect on self-confidence and social activities participation

The interviewer reported a mutually-supportive relationship within the groups. In his view, this helped to raise members' confidence while all supporters reported participants becoming more confident. One commented "participants appear to be growing in confidence. I believe this is due to the groups' activities and the interaction/socializing of participants". Diaries show that confidence took time to develop but, slowly, members became more assertive when talking with visitors or when on visits, interacting with the public or shopkeepers. They developed confidence to take their place in society, living the same lives as everyone else: they queued to buy tickets, they bought refreshments and souvenirs, and they chatted. Some members also became much more confident in visiting the different food outlets where they live.

A wide range of local community members are regularly invited to talk about their culture and run workshops for the group. On one occasion, this resulted in a guest being invited to the 'women's group' the member belongs to. Community members have also been invited to take part in an oral history project one of the groups had been involved with. Diaries show that community guests often express their surprise at how much they enjoy the visit and confess to having been slightly apprehensive to come. One also commented how useful this had been for her as she did not know what the words 'learning disability' meant when she had been invited. Another became very interested when Proud2B members explained to him what an advocacy service

was. This clearly illustrates the advantage of inviting local community members to visit the groups. Inviting them to share their culture or to join the group in projects linked to culture and heritage is usually well-received, and even empowering (Ruiz, 2004). This is a much more positive engagement approach than simply distributing leaflets or giving presentations. Through their visit or participation, community members increase their understanding and awareness of the availability of support for people with a learning disability in this country and, maybe, start overcoming their own pre-conceived ideas and fears. It is hoped that they take this knowledge back to their own community where it could help to encourage more people from minority backgrounds to ask for the support they need.

Specific celebration events provided unexpected opportunities to engage with families. One parent helped with one of these by suggesting recipes and, in the questionnaires, three parents stated that they would be happy to help occasionally. In the oral history project, family and community members were interviewed around the theme of 'Favourite Places'. This provided an opportunity to learn to use new recording equipment and also to find out about people's stories and why they now live in Hampshire.

Conclusion

The Proud2B groups appear successful for the individuals taking part. However, the small sample in this study means that the findings cannot be generalised nor considered predictive. It is also important to remember that, in Hampshire, diversity is lower than average. There are few service users from a minority background but, at the same time, there is a great variety of countries of origin. As a result, families are isolated, there are few community groups and service users seldom have an opportunity to celebrate their ethnic background. This will, no doubt, have influenced the findings of this research. Nonetheless, there is evidence that participating in the Proud2B group has had a positive effect on members' lives. It has resulted in enjoyment, increased awareness of and interest in diversity, heightened sense of self-pride and confidence and increased participation in social activities. This indicates that groups of this type could be beneficial in achieving similar outcomes for other people with a learning disability from a minority background. There is also evidence that the groups have brought bonus effects for staff in their support for members and in terms of professional practice. This could be of interest to service providers. Finally, the research has shown how such groups engage positively with families and the wider community.

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Notes on Contributor

Dominique Rawlings has been working for Hampshire County Council for over 10 years, first in children services and now in adult services. Her background is in education and, as part of the Ethnic Minority and Travellers' Achievement Service, she ran several projects aimed at community engagement and, in particular, improving parents' skills to support their children. In 2005, she set up the Ethnic Minority Learning Disability project for Hampshire Learning Disability Partnership Board in response to the Valuing People agenda.

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