



Hopes and fears concerning service developments:

**A focus group study of parents and family
carers of people with learning disabilities**

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1. Background to study

At present there are a number of changes which are impacting on the way in which services for people with learning disabilities are planned, developed and implemented. Developments such as person centred planning and direct payments have the potential to transform current patterns of service delivery. However, as with any new developments, those affected by them are likely to experience both hopes and fears. One key group of people whose views are important in relation to these developments are parents and family carers of people with learning disabilities. Indeed the Learning Disability Implementation Advisory Group (2006) stress the importance of involving parents and family carers in strategic planning in order to ensure that the end results reflect their needs and priorities.

The Unit for Development in Intellectual Disabilities, School of Care Sciences, University of Glamorgan were thus commissioned by the Parent Forum Alliance within one Unitary Authority in South Wales to undertake this study. The aim of the study was to gather information which could be used by both the Parent Forum Alliance and the Local Authority Community Services Division to inform service planning and development.

2. The study context

Before reviewing the literature concerning parents' hopes and fears in relation to service developments, it is useful to consider the different types of service provision. This is not just an attempt to neatly introduce the topic. The main reason for distinguishing between different services is because often parents' views and concerns vary depending on the type of service provision (Tennyson, McGill & Cooper, under review). Thus, services may be divided in the following categories:

- Respite care, which can be either residential or in the person's own home
 - Residential / accommodation services
 - Day services
- (Best Value Review of Learning Disability Services - accessed July 2005)

Omitted from this list, however, is any mention of other support services (such as health services) and strategies by which overall packages of services may be developed (for example care management and person centred planning). White and Hastings (2004) distributed a checklist of the different types of professional support (Professional Services Support Scale, 16 different types) to parents of adolescents with severe learning disabilities and described the frequencies of services received. The three most used services were found to be: '*careers advice for child*' (82%), '*speech and language therapy*' (61%) and '*social worker visits*' (58%). The three least/not used services were: '*child-minding*' (0%), '*befriending scheme*' (3%) and '*psychiatrist*' (6%). '*Respite care/short-term break*' was used by 27% of the parents and '*home support*' by 30%. The authors suggest that the use of services is correlated more with the child's need than the parents' needs.

Even though considerable advancements have taken place since the launch of the All Wales Strategy for the Development of Services for Mentally Handicapped People (Welsh Office 1983), key questions concerning services remained in the Report by the Learning Disability Advisory Group to the National Assembly of Wales (Learning Disability Advisory Group, 2001). In this report, support services are characterised as *'insufficiently extensive', 'non flexible' and 'inconsistent'*. It is stated that important issues remain in carers' families. The Advisory Group's recommended priorities, targets and performance indicators for parents and carers cover issues such as: *'accessibility of information (local and national)', 'assessment of carers needs', 'improvement of quality of life', 'flexibility of service provision', 'special support for parents and carers who support a child with complex and challenging needs', and 'partnership in planning, development, delivery and monitoring of services'*. In short, the plan in the 2001 report is to provide services for parents and carers that meet their needs, wishes and hopes (Learning Disability Advisory Group, 2001).

In Family Matters (Department of Health, 2001), it is clearly stated that carers must be supported in their own right. The report highlights all the areas in which families with a disabled child can be disadvantaged; namely, *'high levels of stress', 'finances', 'health', 'isolation', 'housing', 'marital breakdown'*. Minority groups can be further disadvantaged in the following areas: *'high levels of unmet need', 'poverty', 'poor housing', 'social isolation and lack of support', 'lack of information', 'lack of culturally appropriate services'*. Three groups of carers are identified as having priority needs: *'older carers', 'family carers from minority ethnic and black families', 'families supporting a young person through the transition from childhood to adulthood'*.

The importance of involving parents and/or family carers in research has been widely recognised. Past findings confirm that the emotional well-being of the parents is based upon their beliefs about, behaviour towards, and social support for, people with a learning disability (Hibbs et al., 1993). This is not a direct relationship, but instead beliefs, behaviour and social support affect first the appraisal system and the coping styles of the parents (Lam et al., 2003).

The importance of undertaking research with parents and/or family carers has been also noted in a recent conference conducted by the National Institute for Mental Health in England. Results of a research priority setting exercise include amongst others the priority of *'families' views on services; how do we put this information into practice'* (McCombie and Chilvers, 2005).

Walden et al. (2000) conducted structured interviews with parents and detected that satisfaction with informal and formal support from services correlates with parents' quality of life. According to the authors, parents perceive formal support from services as positive, in the sense that it gives them a break from the continuous care. However, parents allude to formal support not always being as appropriate (useful), sufficient, flexible or accessible. In addition, cross-cultural variation was found in parents' experiences. This variation might derive from differences in systems, which mirror differences in economic status, cultural norms and attitudes towards

disability. According to Mir (accessed April 2006), minority ethnic groups are marginalized and alienated from current service provision, which doesn't accord with their different values and needs and undermines their fears and vulnerability.

Mothers indicate that their relationships with professionals are inhibited. In a study conducted by Todd and Jones (2003), mothers reported negative experiences, and in particular feeling that professionals hold a judgemental attitude towards them. Even though, most commonly, parental views on services are negatively portrayed in much research, parents appear willing to participate actively in meeting their child's need. One way to do so is by challenging the professional point of view on how to meet the needs of their child.

In a longitudinal study conducted by Carr (2005) with families with children with Down's syndrome, parents showed an overall satisfaction from health services. In the same study complaints were expressed only when a worthwhile service was discontinued. It was identified that respite care services are positively rated by parents, when their value is related to satisfaction of the needs of the child. Research suggests that dissatisfaction and unclear relationships seem to relate mainly to professional and formal services (White & Hastings, 2004)

Redmond and Richardson (2003) interviewed mothers of children with learning disabilities and found that services didn't meet their requirements for good quality service provision. Mothers expressed dissatisfaction both with the learning disability services and the acute medical services. They characterized services as '*uncoordinated*', '*unreliable*' and '*difficult to access*' (Coyle, 1999). Mothers with dependent children also have very reduced employment levels. They attribute this to having to face unusual time demands, and a lack of adequate and affordable child care (Shearn & Todd, 2000). Mothers are not the only ones who suffer employment problems. Fathers as well feel restricted in their choice of occupation and, when they get a post, in their opportunities for promotion (McConkey et al., 2004).

Most of the research conducted focuses mainly on mothers and less on fathers or even siblings. Society has given different roles to mothers and fathers, fathers being the strong ones, the ones that must support the family in the long-term and fix potential problems. Mothers are the ones to deal with the everyday life and the short-term problems of the family. However, the fathers report that the role given to them from the society often makes them feel excluded, isolated and not important in the family context (SchwabLearning.org accessed April 2006).

Studies with demographic information explain the exclusion of fathers from research. For instance, in a study for older carers in Northern Ireland it was found that in families with people with severe learning disabilities 217 of the main carers were mothers and only 30 fathers (McConkey et al., 2004). This not only means that fathers are 7 times more likely to be excluded from caregiving and/or research, but also that mothers are most affected by the

short-term impacts of disability. This explains why fathers' stress levels are found to be comparatively lower than mothers'. This finding illustrates how the generation of stress is associated with the child's daily routines (which impact mainly on mothers' emotional well-being) and less with the disability itself (McConkey et al., 2004).

Valuing People (Department of Health, 2001) has been particularly critical of service provision for families of children with learning disabilities. This criticism is reflected in research, which points to a number of problems with service provision. Literature suggests that children and young people may end up attending a 52-week residential school, mainly because of a combination of social and educational difficulties. It is very common that families with a child with profound behavioural problems find it difficult to cope with their child's behaviour. Their difficulties are compounded by the absence of adequate support from respite care and local services. Lack of adequate support leads parents to mistrust services and seek for residential placements. Families complain that respite centres and local services lack the skills to manage their child's challenging behaviour. After residential placement, parents are found to report satisfaction with the service provision. However, satisfaction must be viewed with some scepticism, because it might just reflect improvement in the family context and not satisfaction for their child's experiences in the residential environment. In addition, more concern must be raised if the vulnerability of these children is considered. Parents themselves express concern that they don't really know what happens in these services, because of the geographical distance, and if their child manages to effectively communicate his or her needs (Tennyson, McGill & Cooper, under review). Such arrangements also raise questions as to what forms of support will be available when the child transfers to adult services.

As noted by parents, it is important to them to make suggestions for future service developments that they would like to see. Mothers, who have reported being happy to care for their child at home, have proposed the development of home-based services. Namely, they need help to be offered in their home environment on a short-term basis, when they need to engage in other activities (Redmond & Richardson, 2003).

Heslop et al. (2002) have summarized research findings about the transition of young people from childhood to adulthood. In their summary they highlight the concerns of the families and the emotional impact that the transition has on families. Families are found to be uncertain and stressed (Todd & Jones, 2005) due to lack of efficient planning and often they considered that the topics important to them during transition planning were not actually reflected in the planning. Concern was also raised concerning a lack of accessible information for the future and in particular about matters of independence, such as '*personal safety and risk*', '*money matters*' and '*transport*'. Positive aspects of transition planning included matters such as the young person being emotionally prepared for change and being able to make informed choices, and that the parents themselves were actively involved in the transition process.

Knox et al. (2000) have studied the views of families who have a child with a learning disability. The authors maintain that the 'client' is the whole family and not just the person with the learning disability. More specifically, they see family not as being comprised of individuals, but as a complex dynamic system, in which changes in one member impact on all family members. The family is also part of the broader ecological system, in which service provision is encompassed. The authors argue the importance of an interpretive approach in which what needs to be taken into consideration is not how services translate events and situations, but how families code and decode their family events and situations. The study they conducted, involved individual open-ended interviews regarding the control families have in their lives and their suggestions as to how to increase such control. Their views concerning control and current mechanisms focussed on three topics namely, '*the family's future*', '*sharing of decision making*' and '*pertinent information*'. Parents were alarmed regarding the absence of services for adult users. They expressed the desire to be viewed as equal partners and not as consumers, and added that sensitivity to their feelings should be taken as given and not as something that they have to ask for. Finally, pertinent information was found not to be accessible. Participants reported either being poorly informed or as not knowing what to ask for.

Todd and Jones (2005) see the family as a complex dynamic system as well. In their paper they discuss the transition from childhood to adulthood of people with learning disabilities and the impact that this transition has on mothers and family in general. They suggest that this is a time of transition not only for the young person with a learning disability but also for their mother who undergoes their own mid-life transition. This is expressed with existential questions and reflected on changes in their physical, emotional and social self. Mothers don't only have to cope with the question "What will my child do after the age of 19?" But also with the question "What am I going to do at this time?"

Tennyson and colleagues (under review) have found parents to be '*extremely worried*' about the availability of suitable future services. As far as direct payments are concerned, parents might think that they automatically mean that their child will want to leave home, while instead they may be used to support them at home and/or at college (Joseph Rowntree Foundation, accessed 2005). It is worth noting that a common fear amongst mothers is not to be labelled as selfish, when the focus is placed on their own needs (Todd & Jones, 2003).

It has been suggested that parents worry so much about what will happen to their children after they die that they pray that their son or daughter dies first so they will not be left fend for themselves (Bogues, 2004). Older carers have fears, which mainly generate from their anxieties about the future. They feel uncertain about who will support their family member with learning disability after they die. Others express concerns about self-neglect, harassment, abuse and stigma (East Sussex County Healthcare PPI Forum, 2005). Services for people with learning disabilities have profoundly changed through the years. However, older carers may not be aware of the present reality. For

them it's frightening to discuss their hopes and fears for the future, because *"nobody will understand"*. They have often been disappointed in the past and now they find it hard to open up to service providers. In addition, they argue that the format of information is not easily accessible (Magrill, 2005).

In a publication by the Foundation for People with Learning Disabilities it is stated that: *"It is very important to make sure that special work with older families is still part of everything else that is happening for people with learning disabilities, older people and carers"* (Magrill, 2005). In Sheffield there are 2.839 registered people with learning disabilities. Of those 2.839, 413 are over the age of 65 and live at home with their family carers. Only 38 people out of 413 are known to use short break services (Bogues, 2004).

Older carers often find it difficult to speak up about their own needs. Many are unaware of the existence of social services and do not know how to approach services. Older carers, apart from the effort they put to take care of their family member with a learning disability, have to cope with their own health problems and find solutions in everyday domestic tasks (Magrill, 2005). However, they also don't like defining themselves as carers and they don't recognize the physical and emotional impact that caring can have on their emotional and physical well-being (Locke accessed April 2006). However, this is not always the case. In a study conducted by McConkey and colleagues (2004) about family placement schemes, a general satisfaction was expressed from the family carers. In addition, 72% of the participants were found to have no suggestions for the scheme's improvement.

McConkey et al (2005) highlight a group of carers, which is unfairly treated, namely lone parent carers. The authors found that lone parent carers over the age of 65 suffered poorer physical and emotional health and financial problems, whilst lone parents under the age of 65 had fewer chances to be employed. Tasker (2001) states that part of the Carers Special Grant by the Department of Health is there to satisfy the priorities of older carers of adults with a learning disability.

There is a long tradition of caregivers being included in research. However, some key aspects of care giving experience have been neglected. Research has mainly recruited participants via convenience samples, autobiographical and biographical accounts. In addition it seems that more research has focussed on the views of mothers rather than the experiences and views of fathers. Little is known about how families manage without family support services. Also, there is little research on the role of family carers in planning changes and development in services. Finally, demographic factors need to be taken into account to explain the differential views of parents and carers such as those which arise due to differing geographical locations or different stages in the life cycle. Families should thus be included in research not only to better understand their experiences, but also to examine their role in service planning (an area under explored till now). It is suggested that the interests of families and people with learning disabilities should be seen not as conflicting, but in a holistic way as contributing towards the well-being of the whole family (Grant & Ramcharan, 2001).

This literature review reflects the empirical and theoretical background upon which the current project aims to build. It has sought to identify the concerns, experiences, fears and hopes of parents and family carers as well as their views concerning services and service development. It also provides a wider context within which the findings of the current study can be placed.

3. Aims of the project

As has already been noted the key aim of the project was to gather information which could be used by both the Parent Forum Alliance and Community Services Division within one Unitary Authority to inform service planning and development.

Specifically the question it sought to address was 'What are the views of parents and other family carers within the Unitary Authority regarding current and future service developments?'

4. Study design

In seeking to address the research question a key consideration was the choice of methodology and method. One possible approach would have been to undertake a postal survey (based upon the issues raised in the literature) of all parents and family carers within the area to gather their views. Whilst this would potentially have enabled the bringing together of a wide range of views postal surveys do have notoriously low response rates, they can gather superficial information, and it can be more difficult for respondents to raise issues of particular concern to them since the questions are pre-set. For this reason it was decided to take a qualitative approach since this would allow both for the exploration of views in greater depth and for issues of concern to participants to be raised.

4.1 Method

The data in this study was gathered primarily via focus group interviews undertaken by two University based researchers. One of the researchers has previous experience of using focus groups in a number of research studies.

Cambridge and McCarthy (2001) maintain that focus groups help parents and carers to communicate their experiences, understandings, perceptions and perspectives on certain issues. Focus groups also allow for any differences in outcomes correlating with age, level of disability and geography (Kitzinger, 1995; Lewis, 1995). However, it was recognised that some parents or family carers might not be able to attend such groups due to personal circumstances. Provision was thus made for individual interviews to also be conducted if necessary.

The areas explored in the focus groups and interviews included:

- The range of service currently available

- Satisfaction with current service provision
- Parents/ carers knowledge of planned service developments (suggested prompts include educational, day, work, health, and leisure services, transport as well as direct payments and person centred planning)
- Their fears and hopes in relation to proposed service developments
- Their views concerning developments they would like to see but which are not being planned.
- Their views concerning current mechanisms for involving parents and carers and their suggestions for developing and extending these.

This topic guide was developed by discussion with members of both the Community Services Division and the Parent Forum Alliance as well as taking account of issues raised in the literature. It was then refined following a pilot focus group, undertaken with 8 participants, which was held to test both its comprehensiveness and its acceptability to participants. Only minor changes were made to the sequencing of questions.

4.2 Sample

Given the qualitative approach undertaken within this study the aim was not to survey the views of a large sample. However, it was felt important that all parents and family carers were provided with the opportunity to contribute if they so wished. The population of 911 parents and family carers within the area were thus contacted by post and invited to participate within the study. As well as providing the opportunity for everyone to participate it was hoped that such an approach would also ensure that the resultant sample would be representative in terms of level of disability and age of the person with learning disabilities.

In total 71 responses were received from people agreeing to participate. Unfortunately, however, the number of people eventually participating fell to 33. A number of reasons emerged as to why there was such an attrition rate. First, in some instances, the letter of invitation had been sent to the person with learning disabilities rather than their parent or family carer. Given the particular focus of the study it was not appropriate for them to participate and so they were thanked for their interest. In other instances the wrong telephone number had been given in the information returned to the University and postal contact did not elicit a response. Yet other family members and carers expressed the desire to take part but the practicalities of caring and family circumstances (holidays, illness and bereavement) precluded involvement. Finally some respondents had already taken part in the pilot focus group thus precluding involvement in the main study.

Four focus groups were thus held with 13, 7, 3 and 6 participants respectively. In addition three interviews were undertaken with 4 participants (one interview was undertaken with both parents). Table 1 below provides information concerning the age of the person for whom participants were providing care and also their level of disability. It can be seen that the sample did, therefore, include both parents and family carers of those who were within the transition

period as well as those who are older and that it also included those caring for people with varying degrees of learning disability. Nonetheless it is important to note that level of disability refers to the self reported level as perceived by the parents and family carers. It was not verified via seeking a formal diagnosis. Six of the participants were male and 27 were female.

		Number of participants
Age of person cared for	14 – 25	15
	26 – 17	17
	66+	1
Degree of learning disability experienced by person cared for	Mild / moderate	12
	Severe / profound	21

Table 1: Characteristics of sample

4.3 Data analysis

All focus groups and interviews were tape recorded, transcribed and imported for coding and analysis into NVivo . NVivo is a software package which assists in the process of qualitative data analysis by allowing researchers to code individual sections of data according to themes and categories and then to retrieve data coded in a similar way across different transcripts. It thus allows for comparing and contrasting of data across the range of focus groups and interviews.

Within this study the data were coded in two different ways. First a descriptive coding was undertaken to allow for the identification of comments associated with the age of the person cared for and their reported level of disability. Second a thematic analysis was undertaken in which categories of data were determined a priori by the topic guide used for the focus groups and interviews. Transcripts were then read and re read by the two members of the research team who had been involved in data collection. Emerging themes were then identified and the transcripts were coded according to the identified categories and themes. Inter- rater reliability was promoted by a third member of the research team independently checking the coding: a high level of agreement was found.

4.4 Ethical issues

The key ethical issues in this study related to non maleficence (to do no harm), beneficence (to do good), confidentiality and consent.

It was not anticipated that the study would cause harm to participants but it was recognised that some participants could express dissatisfaction with current or planned service arrangements and that this could cause some distress either to themselves or other participants. However, it was stressed in the information sheets provided that this study was an opportunity to feed

views and feelings into the service planning process. Those facilitating the focus groups were experienced in dealing with such situations and where any minor distress was apparent they spoke with the participant concerned following the focus group / interview and suggested possible sources of support if required.

In relation to beneficence it was recognised that it would be unlikely for participants to experience immediate or direct benefit in terms of changed service provision for their relative. However, it was stressed that participation in the research study did provide the opportunity to influence the service planning process.

To maintain confidentiality all information inviting parents and family carers to take part in the project was sent out by the Community Services Division thus ensuring that no details concerning individuals were passed to the research team without their consent. Since all responses were sent directly to the University this further maintained confidentiality since neither the Parent Forum Alliance nor the Community Services Division were aware of who responded and hence who participated (unless the participants themselves chose to disclose the information). It was also made clear in the information provided for potential participants that quotes from focus groups or interviews would be used anonymously in the project report and that information from the study would be used (anonymously) in journal papers and conference presentations. It was also stressed that any information provided would be stored securely in accordance with University policy.

In order for consent to be obtained it was necessary to provide full information concerning the study and the nature of the participation which was being requested. A letter of invitation, participant information sheet and a proforma requesting initial information were thus sent out to potential focus group participants (Appendix One) and potential interview participants (Appendix Two). All participants were asked to sign a consent form before taking part in either a focus group or an interview (see Appendices One and Two).

Ethical approval for the study was sought and obtained from the School of Care Sciences Ethics Committee prior to commencement of fieldwork.

4.5 Project management

The day to day management of the project was undertaken by the principal researcher (Professor Ruth Northway) and the Research Fellow (Iliana Sardi) along with other members of the research team (Ian Mansell and Robert Jenkins). However, the overall progress of the project was monitored via a Project Advisory Board comprising members of the research team, parent / carer representatives and representatives of the Community Services Department. The Advisory Board met regularly throughout the study period and was involved in commenting on the development of both the study protocol and the supporting documentation.

5. Findings

As discussed data gathered in the focus groups and interviews were analysed and coded using the NVivo software package. The emerging categories and themes are presented in Table 2 below. In the section relating to data analysis it was stated that the categories were determined by the areas identified in the topic guide. It should be noted, however, that when the actual analysis was undertaken it became apparent that it would be more logical to merge some initial categories. First when participants spoke regarding their knowledge of current services this was often directly linked to discussion of their satisfaction with these services. These categories were therefore merged into a single category of 'Knowledge of, and satisfaction with, current services'. In addition the initial category 'Knowledge of planned services' generated little discussion and thus was also included within the category 'Knowledge of, and satisfaction, with current services'. Finally discussion of 'Developments which are desired but not planned' has been merged with 'Hopes and fears in relation to proposed service development' since discussion of these areas in the focus groups and interviews was often linked.

Category	Themes
Knowledge of, and satisfaction with, current services	Education Respite care Health services Professional support Employment Day services Direct payments Accommodation Care planning Help at home Awareness of planned developments Having to fight Needing to shout Needing to be proactive
Hopes and fears in relation to proposed service development.	Hopes Fears Services which are desired but not planned
Views concerning current mechanisms for involving parents and carers	Communication with the Parent Carer Alliance Communication with Social Services

Table 2: Identified categories and themes

The findings of the study will be discussed in relation to each of these categories and themes. Quotes will be used to illustrate the issues raised by

participants. These are included verbatim to reflect what was actually said. One exception to this is Interview 3 where technical difficulties meant that the tape could not be clearly transcribed. In this instance field notes made by the researcher have been used to highlight any areas where this participant concurred with, or deviated from, views expressed elsewhere. The findings will be discussed in the context of wider literature to identify where issues raised reflect, or contrast with, issues raised elsewhere.

5.1 Knowledge of and satisfaction with, current services

The amount of knowledge that participants had regarding current services varied a great deal. Some participants had little knowledge of any services other than those they currently used whilst others had heard terms such as direct payments, independent living fund etc. but did not have information as to what the terms meant. On occasions individuals used the focus groups to ask fellow participants for an explanation about these terms.

Some of the themes to emerge related to specific forms of service provision whilst others related to views regarding mechanisms for accessing services and equity of provision. Each of these will be discussed in turn.

5.1.1 Education

Education was discussed in three focus groups and in two interviews. Education was seen primarily in a positive light although some individual parents and carers had had mixed experiences as illustrated by the following comment of a parent of someone aged 14-25 who has severe learning disabilities:

'Well, the school that my son is in now is great, he loves it and we love it and the actual individuals there and the teacher in charge of the unit have been really good and the one to one support and the lessons are good but it is chance I think, because the previous school that he was in, you have got your annual review, you would suggest things and they would say "Yes we will do that" following year you could still be suggesting it because they still haven't done it and that happened every year until he moved onto a different school.'
(Focus group 1)

Some participants suggested that it was due to their persistence and / or knowledge of the system (gleaned from their own professional backgrounds) that had led to positive developments. Some concerns regarding transport and the issue of transition from education to adult services were also apparent.

In relation to transport there was evidence of differing experiences with some parents in Focus group 1 reporting difficulties in accessing transport to their first choice school if it was out of their area, whilst other parents in the same group reported they had had no such problems. This is one example which

emerged in the focus groups and interviews where service provision within the area appeared to vary. Where difficulties were experienced they were seen as limiting parental choice in relation to desired schools. The Learning Disability Advisory Implementation Group (2006), however, stress the need for education and transport services to work together in order to support lifestyle choices.

Planning effectively for the transition from child to adult services is viewed as one of the 'most significant changes' which occur in the lives of people with learning disabilities since it is particularly important in relation to longer term outcomes (Learning Disability Implementation Advisory Group, 2006). Nonetheless Hudson (2006), based on his research in England, suggests that the transition from child to adult services is characterised by discontinuity rather than continuity. Transition was an issue that caused concern amongst participants in one focus group with one parent suggesting that there was limited confidence in the transition process.

'I suppose that I am at the stage of my son being at transition age and I understand what should be happening not that it is happening you know in terms of the process for transition I think that it is very woolly it is not made clear to people and that in fact the only reason that he's beginning to evolve a transitional plan is because I'm driving it forward.' (Focus group 2)

This reflects the findings of Hudson (2006) who argues that planning is often left until the last minute being reactive rather than occurring over a longer term basis. A participant in the same focus group (the parent of an older son) confirmed that this also reflected their experience:

'I can relate to that. My son is 21, he has gone through the transitional stage, education was superb and they worked very hard with him but the plan wasn't followed through.' (Focus group 2)

The discussion within this focus group appeared to cause some anxiety with one respondent, the parent of a young person with mild learning disabilities commenting that:

'Education itself the school was absolutely brilliant, couldn't fault the school [Participants: yeah] but I have got real trepidation for her going into social services now.' (Focus group 2)

Such views reflect those expressed in other research where transition planning was not viewed as being efficient thus resulting in uncertainty and stress for the family (Todd and Jones, 2005).

5.1.2 Respite care

Respite care can make the difference to a family's continued ability to provide care (Bogues, 2004). It can also assist with planning for the longer term move

of an individual with learning disabilities away from the family home. This latter idea of preparing the family for the inevitable change and move to a form of supported accommodation was raised by an interview participant, the parent of an adult with mild learning disabilities, who suggested that respite care was a means to this end:

'It's preparing him mentally somehow, you know as if to, because I always used to think when we started having regular respite, I thought the ideal thing to happen was that he would go regularly and often and that would become part of his life to such an extent that he would see that as his permanent and come to us occasionally you know. Of course it doesn't work out like that but and instead he's come far more, not dependant on us but just part of.' (Interview 2)

There was, however, some confusion within the groups regarding the level of entitlement for respite care. Some participants indicated they insisted on a figure of 28 days respite whilst other participants suggested they received much less. The need for assertiveness was suggested:

'I have found out about this, so I had my new social worker and I said "I need some more respite" "Oh well we could put it up to fourteen" "No", I said "I want twenty eight days" and she has given me twenty eight days and you know in the last twelve months I have had it, but I have had to fight for that, it is not offered, you know, no-one makes anything easy for you' (Focus group 1)

A participant in interview 3 suggested there were problems with respite care in one area with not enough activities taking place and suggesting his offspring was unable to find out who would be using the respite care house at the same time (to check if friends were in situ) owing to the information not being released due to data protection requirements. Thus his offspring was declining to attend.

Participants shared stories of needing, but not being able to access, respite and there were anxieties that respite provision was being reduced, partly owing to emergency admissions. However, it was also suggested that obtaining respite care in an emergency can be problematic as one parent of an adult with severe learning disabilities observed:

'If anything comes up with respite care, as an emergency, my wife was taken into hospital and lucky enough I have got a daughter but she lives in (name of town), she had to come all the way down but if something happens you can't depend on social services somebody that your child can go into care within twenty four hours...' (Focus group 1)

Bogues (2004:9), in her study, found that parents often wanted relatively small amounts of respite care but they did need it to be 'flexible, available in emergencies, and bookable well in advance'.

5.1.3 Health services

The Learning Disability Implementation Advisory Group (2006) believes that people with a learning disability have the same rights of access to health care services as the wider population but also note that, despite their increased health needs, they do not always receive an appropriate level of health care. Health services were discussed in all focus groups and two interviews. A mixed response was received in relation to both the knowledge of and experience of health services received by participants and family members. These ranged from an interview participant who had never used health services explaining that her offspring was not ill but simply had a learning disability and had thus never required them, through to some good and bad experiences of hospital care. Such mixed views are also evident in the wider literature with some parents indicating an overall level of satisfaction with health services (Carr, 2005) whilst others (for example Band, 1998; Bogues, 2004) reporting less favourable experiences.

Some of the positive statements included the following from the parent of an adult with mild learning disabilities:

'Generally speaking I don't think we've got a great deal of complaint, because when we've needed them, they've reacted and been as well as we would wish them to. They were brilliant, no complaint at all.' (Interview 2)

A second participant, the parent of an adult with severe learning disabilities, also commented favourably:

'the doctor I mean I can't fault them and anything that I am worried about at that time um you know I just have to ring the social worker and she will contact Dr. ...and she would come up or send a Registrar.' (Focus group 3)

However, the majority of the comments were less positive. There was a feeling expressed that children received a comprehensive health service but that this stopped at transition. Following transition there was a perceived greater reliance on GP services and these were patchy in terms of the quality of the services received, with some GP's have limited understanding of the needs of a person with learning disability:

'I am just saying that once (name) was 16 then you no longer have any... I mean physiotherapy, occupational therapy and seeing a paediatrician on a regular basis but then once you get to 16 you are just sort of, you know left floundering really.'(Focus group 4)

A similar reduction in specialist health services was noted by Band (1998).

There were also examples provided of care that clearly was felt to be inappropriate. In relation to hospital care the following comment was received:

'When we go to the hospital, when we take our daughter to the hospital, they give us a bed, our daughter lays in the bed and that's it, we haven't had a drink for hours, nothing to eat for hours and I have got to say "Do you mind sitting with our daughter when we go and have a drink. They look at us as if they expect you to look after the person you bring in.' (Focus group 1)

Band (1998) found that 63% of the family carers in her study said that they had been expected to remain with their son or daughter with learning disabilities whilst they were in hospital and Bogues (2004) also reported that parents felt obliged to stay. The above participant, the parent of a daughter with severe learning disabilities, went on to say that there was little understanding of the needs of people with a learning disability indicating:

'I have seen the doctor for twenty minutes and we have been sat in the panel seat for over two and a half hours. We have our daughter there kicking the chair and banging and we have complained about it and he just said "Well I treat everyone the same, I don't put no-one before.' (Focus group 1)

Such behaviour reflects a misunderstanding of equality issues since simply providing the same service to people with different needs results in an unequal and potentially unjust service which fails to take account of additional needs.

This lack of awareness was also commented upon by participants in other focus groups and is reflected in the wider literature (for example Learning Disability Implementation Advisory Group, 2006; Band, 1998; Bogues, 2004) :

'The health staff don't seem to be able to cope with somebody that has got additional difficulties, when my son broke his arm, three anaesthetics in three weeks and I ended up taking out his stitches because the nurse was afraid to do it, which was ridiculous and I said, "if you're just quick just do it" talk to him and do it.' (Focus group 2)

'And then the medical people, they know nothing about learning disability.' (Focus group 4)

Band (1998) found that there was limited understanding in relation to communication, safety, degree of self care skills, special diets and level of care required. The need for disability awareness training of all health care staff has thus been stressed (Bogues, 2004).

5.1.4 Professional support

A recent policy consultation document stresses that all people with learning disabilities should have a named care coordinator or care manager (Learning Disability Implementation Advisory Group, 2006). The role of such professionals was discussed in all focus groups and two interviews. The role of the social worker, care manager or community nurse was clearly identified to be the key factor in the quality of the service received by families. Professionals were also identified as the main gateway for the information gained about services and thus having the support of a good professional greatly enhanced access to services. However, participants relayed stories of parents and family members they knew that had no access to professional support, or stories indicating that the professional was ineffectual in helping to meet needs.

Some differences in access to professional support related to age were evident as illustrated by an exchange between participants in Focus group 1. One participant in their 70's, with an adult child in their late 30's, indicated that they were only now in the process of beginning to access personal care for their offspring. Until now they had coped on their own but had found it increasingly difficult. To this another participant, the parent of a young person with severe learning disabilities, responded:

'It shows the difference, because my daughter is fifteen and I have been having home care coming in to give her breakfast, get washed, dressed for school for the last seven years.'
(Focus group 1)

Some concerns relating to the transition process to adult services were also, once again, apparent:

'I have had a social worker, we had a really good one an occupational therapist has been coming into me for the last few weeks to sort things out for me and I mean I am beginning to get worried now, does it change when they hit adult?' (Focus group 1)

The personal qualities of professionals were seen as impacting on the quality of service received. One participant indicated that:

"The quality of the social worker is vital because that is reflects on the quality of the service you receive." (Focus group 1)

A second participant, in a different focus group, suggested that:

"I think it depends on who you have as a care manager and how good they are." (Focus group 4)

Another participant, the parent of a young person with mild learning disabilities, suggested that both competence and honesty were important:

'I always go through my social worker. I must be honest, he is very good you know if I had a problem or I needed anything, I think he would action it but then he, you know if it was something that I really wanted and it is not there, he would just say well it is not there' (Interview 1)

This was supported by a participant in another focus group who indicated:

'I mean (sons' name) social worker comes about every six months because you know they have to fill in a, an update of their care plan so she comes every six months but I know that she is, if I am worried about anything, I ring (social worker's name) their offices, if she is not there I leave a message and she always rings me back.' (Focus group 3)

Despite good relationships there was recognition that even if the professional was supportive they still may not be able to provide the services requested. This on occasions was felt to prove frustrating to both parties:

'You can have wonderful social workers and they can be really good at their job, but then they go back to their line manager or whoever is next to them and there is no money available, so the social workers are just getting so frustrated,' (Focus group 1).

There were also frustrations regarding the continuity that was provided and the feeling that even if you had very good support it was likely that this person would in time move on. A participant indicated that:

'...the social workers, if you get a good one, then usually you don't keep that social worker because they have a promotion and they move on and so you start all over again with somebody else.' (Focus group 2)

However, there were strong suggestions that the professional allocated did not always support the family member and hence services could not be accessed:

"The one we have now he's very good, but the one prior to that if you needed to have some response to something you couldn't even get her to respond to calls, she was either out or she hadn't come in or when I called again in ten minutes she'd gone out.' (Focus group 4)

The need for reliability and consistency of approach has also been noted elsewhere (Bogues, 2004).

5.1.5 Employment

Employment was discussed in two focus groups and one interview. One participant, the parent of an adult with severe learning disabilities, expressed the wish for their son to have employment but also expressed concerns that the support required may not be available:

'...my God wouldn't I love my boy (son's name) to have a job, I would love him to be employed and independent but he is never going to be that way unless he has constant care, 24 hour care...' (Focus group 1)

Another participant recounted how work experience had provided a sense of importance for their daughter but that this experience had been temporary:

'Before my daughter left school she would go a morning a week to a factory where she did simple tasks, she felt important that she used to be "going to work this morning" the factory closed down and nothing further was explored, but if all the clients for their abilities could be given some sense of importance...' (Focus group 4)

However, another participant spoke of the good service which they were currently receiving (which included work experience) but for which funding was time limited:

'...but I know a group that has been absolutely fantastic with me called (Name of service) and if they hadn't come in on my side he would have had absolutely nothing but now they take him out four days a week. He has work placements, he has leisure facilities with them, he goes to college with them, but this is the pilot, once the funding runs out, I will be back to square one...' (Focus group 1)

The Learning Disability Advisory Implementation Group (2006) have thus stressed the need for a variety of strategies to support employment which include matching vocational training to the job market, assessing the support required to gain and sustain employment, and ensuring a range of locally available options.

5.1.6 Day services

Day services were discussed in all four focus groups and in each of the interviews. Whilst some participants were supportive of day services the majority had negative comments. Some aspects of day services in particular were singled out for criticism with participants suggesting that in some settings there is not much meaningful activity.

A positive comment suggested:

'(son's name) goes to (Name) Day Centre and it is quite a big range of activity to suit all people with different disabilities and I am quite happy what (son's name) he has got.' (Focus group 1)

However there were many negative comments suggesting that there were problems with what were perceived as traditional services. The following comment was made by the parent of an adult with mild learning disabilities indicating that they take in their own activities due to a lack of stimulation:

'Two days a week my daughter goes, simply because there is little there to accomplish these days, she actually takes knitting or crochet or um, embroidery whatever to keep her occupied.' (Focus group 4)

The concept of lifelong learning was raised on a couple of occasions with one participant suggesting

"There is no provision whatsoever within day services for lifelong learning for the majority of individuals if they've got anything other than a mild learning disability then there's put within the day centre environment which is absolutely appalling and my opinion is they are holding pens." (Focus group 2)

This is of concern given that the need for people with learning disabilities to access a variety of forms of lifelong learning has been noted (Learning Disability Implementation Advisory Group, 2006). Another participant reported that whilst their offspring had a good experience within the day service setting, they felt that this was not the case for everyone.

'My daughter, for instance goes to the day centre five days a week and she's got one to one care every day and because she has got the one to one care she's then able to access things that other people can't access so she goes to the pottery, she goes um to sports centres she goes to dance classes and my daughter has got profound learning disability and there're a lot more able people who are just simply sitting in day centres, like you say, and they only go two days a week because their parents don't want them just sitting there knitting, or watching the television and they think it is a waste of their time so they let them go two days a week because that allows them social contact.' (Focus group 4)

There was also a perception that day services were understaffed or under resourced with a feeling that money was wrongly directed to paying office based professional staff rather than spending money on staff who deliver hands on services:

'But I think also there's a lot of more profoundly disabled people who get forgotten about. I mean the day centres are full of people who um, have either got challenging behaviours or they have got a profound learning disability and they need somebody to sort of look after their physical needs, they need to be fed and they need to be in someway amused one to one and there is just not enough staff to go around and I think that half the problem is that they're spending so much money paying professional people to sit in offices telling everybody what should happen instead of actually spending the money on the people on the ground who work actually hands on with people with the learning disabilities.' (Focus group 4)

There thus appeared to be some suggestion that the quality of service received may be linked to level of disability although views as to whether having a profound or multiple disabilities meant a better or worse service varied.

The decision to open satellite day services and the benefits these may achieve was also questioned. Participants felt that there had been little consultation prior to these being developed. Some of the units were thought to be in less than appropriate settings with problems with staffing identified and on occasions clients having to be returned to the larger centres owing to staff shortages:

'And it's a little building with wire over the windows, high fence all around, so nobody sees them and they can't see out.....A lot of these satellite units were rather rushed in.' (Interview 2)

A second participant, the parent of an adult with mild learning disabilities indicated:

'...you know he is much more happier going back to the main one where there are structured things for them to do you know, but we weren't even consulted about it. We didn't even know until, we were just told well, "next week he is going on this bus and he will be in the satellite unit" and it took a while for them to take him back to do the things he liked to do in the other one.' (Focus group 2)

5.1.7 Direct payments and the Independent Living Fund

Discussion concerning direct payments was limited within the focus groups and interviews and the views expressed were mixed. One participant (a carer of someone with severe learning disabilities) who was in receipt of Independent Living Fund payments commented favourably upon this provision:

'it is excellent, it gives you a break and it gives the person that you look after and outlook it does, they take them out and about, they look after them, all of it, they do.' (Focus group 1)

Another, who is in receipt of direct payments, discussed the responsibilities which such payments place on the carers. However, the benefits were seen as outweighing the costs and the availability of support was noted

...but I had really good support and continued to from the Centre for Independent Living and he had direct payments and they're really flexible and it works really well for us and I asked them to cost up the care plan and they came back with a silly figure so I sent them away to re-cost it and they came back with an acceptable figure and that's, I mean it's more responsibility on me but it's best to use my energy putting his direct payments into place than it is going to beat up the local social services. (Focus group 2)

Such views confirm the suggestion that the provision of both direct payments and support schemes can provide the potential for better matching of support to individual need (Learning Disability Advisory Implementation Group, 2006). However, the comment also reflects the findings of Williams et al (2003) who found that parents in their study had to be 'strong and determined' in relation to direct payments.

Other participants, however, felt that the information provided concerning direct payments was insufficient. As one participant, the carer of someone with a mild learning disability currently undergoing transition from child to adult services commented:

'You ask about direct payments and you're given this little leaflet, I got the leaflet in my bag and it doesn't tell me anything, it doesn't tell me how I am going to do it, how I am going to employ people, have I got, is there employment law linked to this, all of these things it doesn't tell you and the same with the Independent Living Funds they are there I know there's pots of money but how the hell they access them I haven't got a clue!' (Focus group 2)

Another participant in that focus group indicated that they knew nothing about direct payments and one participant in Focus group 1 indicated that whilst they considered themselves to be 'clued up' they similarly didn't know about direct payments. This low level of awareness has been noted elsewhere (Bogues, 2004) and in the study undertaken by Williams et al (2003) they found that at least 9 of the 29 parents interviewed had not heard about direct payments. They thus conclude that both information and support are needed. Such a low level of awareness is a cause for concern given the suggestion that direct payments can play a key role in the transition process (Hudson,2003) which, as has already been noted, can be problematic.

One participant (the parent of a young person with severe learning disabilities), however, expressed the view that it was difficult for people with learning disabilities to access direct payments:

'I have a fight with direct payment at the minute, In (name of area), there are about forty two people in receipt of direct payment and out of those forty two people, this is a rough figure mind, there is only about four people with learning disabilities that get this' (Focus group 1)

5.1.8 Accommodation

Comments relating to accommodation were received from participants in three focus groups and two interviews. A range of issues were raised under this heading. These included waiting lists for accommodation, the need to move on from the family home to achieve independence and parents' and family members anxieties regarding service provision when they are no longer in a position to provide the main caring role. Anxieties regarding tenancies and the ability to live in the family home following the parents passing were also raised as were parents being excluded from the caring role once their offspring had entered supported housing.

In relation to waiting lists for accommodation one participant suggested:

'I am not having it you know and something will have to be done. She is on a list now to go into a group home but I have been told there are twenty five to thirty people on the list above her and it is never really going to happen.' (Focus group 1)

One participant indicated how pleased they were with supported accommodation but felt the only negative element was that this was often not available in the individual's own community:

'But the only thing with supported accommodation, it's brilliant I think it's really good for people because it gives them independence but then they can't have supported accommodation in their own community.....if they are going to go to a supported house they have got to go wherever the social worker decides to put them I live at the top of the valley, they could end up down in (name of town) or wherever.' (Focus group 2)

The anxiety regarding perceived vulnerability of tenure in properties was expressed by a participant (the parent of a young person with severe learning disabilities) who suggested that:

'One of my main worries is what if they decide, I mean at the moment he is supposed to be a tenant within this building now I have never seen a tenancy agreement.....so what happens if, I mean he's quite happy living there but what if somebody decides, well hang on, he's not living there any more and he has to move.' (Focus group 2)

However, a recent report to the Welsh Assembly Government (Learning Disability Advisory Implementation Group, 2006) recommends that individuals should be consulted about housing, tenancy and support arrangements wherever possible.

The feeling of being excluded from a meaningful role once your offspring entered supported accommodation was made strongly by a focus group participant who stated

'Now that's something I am having a problem with because my daughter has been, for the last six years, from residential care to supported accommodation now and I mean it was only a chance phone call that I knew that my daughter was having her eyes tested yesterday, they don't let you ..know what happens from day to day so you do feel, well I'm not worth it any more.'(Focus group 4)

5.1.9 Care planning

Despite the importance of care planning, and the introduction of person centred planning processes, discussion regarding these aspects was limited. Care plans were discussed in two focus groups and two interviews. Although, there were a limited number of comments, the main points made were regarding how progressive or not care plans were.

A participant in Focus group 4 suggested:

"Do you find with care plan and you look at today's care plan and you can go back ten years and it's almost word for word? Not a lot of changes... keep him occupied to find different things and there's very little difference in care plans then to what they are now". (Focus group 4)

A similar view was expressed by a participant in another focus group and supported by other participants in that group:

'They seem to just go over the previous one [Participants: yeah] all the time and very little gets added and very little gets followed up and very few promises are kept.' (Focus group 2)

An interview participant, reflecting on the different terminology which had been used over the years in relation to individual planning suggested that:

'We had this talk about it was going to be about every aspect of life you know and it sounded wonderful you know but you get a bit cynical after a while.' (Interview 2)

It would thus appear that there was a perception that whilst the names given to plans may vary very little has actually changed in practice. However, one participant in Focus group 4 made an even more worrying comment:

'I haven't even seen my daughter's care plan recently and I did speak yesterday with the social care worker, I phoned him and left a message, he did actually get back to me two days later. But I haven't even seen my daughter's care plan.' (Focus group 4)

Without access to their daughter's plan it is difficult to see how this parent can be actively involved.

5.1.10 Help at home

The Learning Disability Implementation Advisory Group (2006) state that domiciliary and other forms of support should be available in order to assist families in achieving their positive goals in ways which they find helpful. However, discussion regarding support in the home was limited. There was a feeling in the focus groups that domiciliary care services had declined rather than improved over the years and were unlikely to be available when required. This was indicated by a participant, the parent of an adult with severe learning disabilities, who suggested that despite their current age (72) they were struggling to secure a small amount of weekly support:

'(20 years ago) I had a carer in the morning and I had a carer in the afternoon to look after him for me to work and now I, you know I am trying to get 3 hours a week now for (son's name), just to take him out shopping and there seems to be a lot of obstacles so I think to myself, you know is this progress!! Whether they spend money on more important things or not, I don't know.' (Focus group 3)

A second respondent suggested that a lack of support may be impeding her daughter's progress:

'More available support staff would be one thing but they seem to be few and far between on the ground. My daughter is capable of quite a number of things.....she knows what coins are she doesn't know their value even when their added together, but she is clean she knows how to do basic cooking, she can do washing, um she can do a lot of domestic things with a little of support from social services she could survive with somebody coming in on a daily basis and saying, "are you alright?" but is it going to happen?' (Focus group 4)

Where support is, however, provided it is seen as having positive effects as exemplified in the following comment:

'He went out last night swimming and had a drink and came home in the car and he, you can see he's livelier.' (Interview 2)

5.1.11 Awareness of planned developments

Participants were asked about their awareness of planned developments and comments were made in three focus groups and two interviews. One participant gave the following response when asked about their awareness:

'Not aware at all.' (Focus group 2)

There was a view that information concerning proposed developments could be difficult to access:

'There are all sorts of services that are available and you ask for information about and you don't even get more information.'
(Focus group 1)

'I don't know if there is anything is there? The only thing I know of is the day centre and support accommodation. I don't know anything else apart from the service (name) which we are using.' (Interview 1)

This latter comment was made by the parent of a young person currently in the transition period and demonstrates that information may not be available at this crucial stage thus giving the potential for stress and anxiety in relation to future provision.

Concern was voiced as to whether funding would be available to support proposed service developments:

'And it's all very well to talk about new proposals and all of that but there has been no evidence over the past few years that sufficient cash is going to be available to improve services.'
(Interview 2)

Concern was also expressed that too much proposed change is not always a good thing and that it can result in little actually changing in practice:

'I think that changes from minute to minute from my experience over the last twenty (odd) years, I mean they've never settle on anything ((participants talking at once)) I think that that's half the problem as soon as they get half way through something they decide to do something else, I mean they talk about planning but it doesn't mean anything to me I mean at the end of the day things have been exactly the same all the way through it has just been so completely confused um at the end of the day as I say it goes back to the level of service you get depends on your care manager and how good your care manager is. (Focus group 4)'

5.1.12 Having to fight

If the literature concerning parents and family carers experiences is reviewed the theme which perhaps recurs most frequently is the view expressed by parents that they have to fight for service provision. Redmond and Richardson (2003) refer to the 'constant struggle' whilst Swain and Walker (2003:553) speak about the 'constant battle to obtain adequate services or resources'. Williams and Robinson (2000) refer to parents as 'lifelong fighters'. Participants in this study expressed similar views with two focus groups expressing the view that it was necessary for parents and family carers to 'fight'. In one instance this related to fighting both for services and for recognition of the demands which caring can exert:

'... the problem is that we look after our people at home it is no fault of anybody that our people have been born disabled, it is just a law of nature and it is just one of those things, but if they were put into government care, it would be costing £350/ £400 a week to look after these people, we get nothing like that to look after them and I find that is very, very unfair and if you do want anything you have to fight, fight, fight right to the end of the road, inside if a checklist given to you, you have a disabled baby this is what you should be having for that child, you have to fight until you are exhausted...' (Focus group 1)

In another instance a parent related how they had had to fight for recognition of the role which they felt they should play in the care which their child receives:

'I think they are appalling, I have to fight, I had a major meeting after the last incident and I had to fight and say "Look I am his mother", my husband said "I am his father" we're not going anywhere and we will be involved in his care' (Focus group 2)'

Information regarding availability of resources was viewed as being helpful, but in and of itself, insufficient in the process of fighting for adequate provision:

*'...but I would say that even with that knowledge and information I still have often felt my back against the wall and have had to do as much kind of fighting as anyone else'
(Focus group 2)*

Concern was also expressed that some parents, such as those who are elderly, may not be able to fight in this manner and hence may not receive the services they need:

'...you know some parents are really elderly and they haven't got the fight in them to go through this, they perhaps haven't got some of the knowledge and the skills or whatever, you know and to have to fight like that for everything, they shouldn't have to at their time of life should they?' (Focus group 2)

5.1.13 Needing to shout

Participants in three focus groups expressed the view that those who received services were often those who shouted loudest:

'...if you know where to look and who to shout loudest at then you can get a little bit more, but otherwise, but even then you know what you can get is limited.' (Focus group 2)

Similar sentiments have been expressed elsewhere (Bogues, 2004). Such a situation was seen as being unfair and leading to inequitable provision of services:

*'...you can see that there are some people that get everything and there are some people who get next to nothing and that's the thing that really worries me about the whole system'
(Focus group 4)*

Redmond and Richardson (2003) noted a similar lack of uniformity in service provision and quality as did McConkey (2005) although this latter study attributed variations more to the differing characteristics of the people with learning disabilities themselves rather than to the characteristics of their carers.

There was also a view that, in some instances, services were provided to those who shouted loudly in order to prevent complaints being made:

'Partly because the people who get a lot of stuff are people who are quite willing to shout about things [Participants: exactly] and they are quite willing to actually find out about what it is they are entitled to and to be honest if you scream loud enough social services will throw things at you [Participants: agree] you know, to stop you putting in official complaints' (Focus group 4)

5.1.14 Needing to be proactive

Participants in three focus groups and two interviews stressed the need to be proactive in relation to securing appropriate services for their relative. In one instance the lack of information provided was commented upon:

'Nobody ever gives you something that says "this is what you need to know" (others agree) you've always got to search, there is always that frustration and you just get worn down by it all. My daughter is only 20 I can't imagine what it's like if you've got somebody about 40 you must be just totally worn out with it all.' (Focus group 2)

Once again the impact of lifelong caring for older carers was noted as an area of concern. In another focus group one participant recounted how they had had to actively seek out services:

'We have been to different groups, one was held in the (name of place), but you have got to go and look for these places' like (name of service) and you find out about respite and different things but you have to go and look for them.' (Focus group 1)

One interview participant commented that whilst they had not been refused service provision they did not feel that they would have been offered it without asking directly for it:

'But we asked for it, I think if we, I don't think it would have been offered to us, I don't, I didn't get the impression but they didn't refuse it and we were prepared to do it and it helped them with me being there you know.' (Interview 2)

The need to be proactive was also commented upon in relation to gaining information concerning the activities of sons and daughters living away from home:

'Well, there again as I said, apart from not being given information about what my son does and where he goes, if I didn't communicate closely, he's in a (name of service) house, if I didn't pick him up every week, speak to the people there, you know, who I must admit are very good, I wouldn't know what was going on you see because I am not told anything if I get the feedback from the workers in the building not actually from the house manager, I get no letters from (name of service) like a progress letter or anything like that, it is just chatting to the staff.' (Focus group 4)

Access to such information would seem to be important in assisting parents and family carers to remain involved in the lives of their adult children.

The effects of not being proactive in relation to service provision were commented upon ruefully by one participant in Focus group 3:

'...you know, I think a lot of the thing is because I think cause the ultimate thing is that cause I've sat back, because they said no I can't have this, I have accepted it and if I had pushed when he was younger I think I would have had a hell of [Interviewer: yeah] a lot more you know things done for him.' (Focus group 3)

5.2 Hopes and Fears

Some of the more general hopes and fears identified by participants have been presented under other headings. However, there were some specific items discussed. This section of the focus groups/ interviews led to some strong feelings being expressed.

5.2.1 Hopes

Discussion regarding hopes was limited with comments being made in only two focus groups and one interview. In many instances hopes were often expressed either as fears that their hopes would not be realised or in terms of desired services and hence are discussed in the sections below. One participant in Focus group 4 did, however, speak of her 'Dark hopes' thus indicating the concerns she had for the future. More positive comments were forthcoming from Focus group 2:

'Yes that it meet what the person wants, that if somebody is allowed to say their wished among these person-centred planning, sort of, the way this system should work, our children theoretically should have should be able to put down their plan. "This is what I want to do, this I where I want to go in five years, this is where I want to be in ten years". I want people to listen to that' (Focus group 2)

'I want people to listen to her for her to have a voice and for them, all these services to say "Ok this is what she wants, right this is what are going to need to do to put that in place for her" and then to do it not say "Oh the budgets don't agree with this" or we you know, trying to, not fit her into this little terrible this day services at the moment but to mould the service around her and around her needs and wants' (Focus group 2)

The desire for services and support to be built around the expressed wishes, desires and needs of individuals was thus apparent.

5.2.2 Fears

Comments regarding fears were expressed in three focus groups and two interviews. There were strong fears expressed about what may happen when parents have gone and the implications for this for other family members. In addition to this there were concerns regarding the potential for the abuse of their loved ones. Also a feeling was expressed that the caring role would last a lifetime.

These statements from participants highlight some of the concerns expressed by participants:

'What happens when we die? What happens to these people because the homes that they can go to are only as good as the people that run them and we see people in the paper don't we, of abusing people and I mean at the end of the day you know you think what is going to happen to these people, its not fair our children should have to look after them, its not fair.' (Focus group 1)

'Yes, are we always going to have the strength are we always going to be around to do it for him what happens because at some point we are going to go, we're going to die, you know we are not going to be around for them.' (Focus group 2)

'I can see us when we're 60 or 70 doing exactly the same... they are going to outlive us and that's my biggest fear, who is going to fight for him, and I've always said to my eldest son "You have a life to lead, you have your life to lead, we will try and put things in place so that you shouldn't have to worry", I wouldn't want him or possibly his future wife, partner whatever would have to take on the burden of his younger brother.' (Focus group 2)

The concern on the part of parents that their sons and daughters may experience abuse has been noted elsewhere (East Sussex Country Health Care PPI Forum, 2005) as have wider concerns as to what will happen when they die (Bogues, 2004). The fact that the need for support would extend beyond their lifetime and the potential implications of this for siblings of the person with a learning disability is an issue of concern for older parents (Jokinen and Brown, 2005). As one participant in this study commented:

'I don't want them to give up their lives just to look after him.' (Focus group 3)

In one instance a participant (the parent of someone with severe/profound learning disabilities) was so concerned about the future that they indicated they would have sought a termination of the pregnancy if they had known of their child's long term support needs:

'And if anyone honestly answered it they would say the same thing because you don't know what is going to happen to your child after your days and that is what is worrying.' (Focus group 1)

Another participant discussed finances and suggested it may not be the fault of service providers if the money required is not available. This participant indicated:

'Ideally there is more money paid into social services so they can provide, I mean in all fairness we are not saying we are not satisfied but they can only provide with what they have got. You can't provide, they can't be perfect because the money is not there.' (Interview 1)

Finally one participant expressed fears about the current waiting list for residential accommodation which impacts upon the potential for planning for the future:

'Unless there's a complete breakdown in their home situation like somebody, you know like somebody just not being able to cope anymore, somebody dying, or something like that, then a planned transfer from home to supported accommodation at the moment is about 10 year waiting list' (Focus group 4)

Such views are of concern given that there are currently some 1,700 people with learning disabilities in Wales living with carers who are aged 70+ (Learning Disability Advisory Implementation Group, 2006).

5.2.3 Services which are desired but not planned

The preceding discussion of categories and themes has already given some indication of changes which participants wished to see in terms of service delivery. However, participants in two focus groups and two interviews commented directly on services which they felt were required but were not necessarily planned. One participant commented:

'That's an interesting question, um one of the things I bleated on for some time is continuity.' (Interview 2)

Such continuity was seen as being needed in relation to staffing levels, individual staff contact and service provision although the relationship between these was acknowledged.

Another participant saw the need for better information to be available:

'For me it would be more information readily available [Participants: yeah] when you're, my husband and I both work and, and so by the time you see to different, ordinary everyday things, um, you know then, to have to go and investigate or look for things...' (Focus group 2)

Similar difficulties with accessing information have been noted in other sections of this report as well as elsewhere (Knox et al, 2000) hence the need for parents and carers to proactively receive full information has been stressed (Learning Disability Implementation Advisory Group, 2006). However, the need for better information is another recurring theme in the literature concerning parents experiences of service provision. Bogues (2004) found that 'without exception' parents and family carers in her study raised concerns about the difficulties they had experienced in accessing information. Similar views were obtained by Redmond and Richardson (2003) and Swain and Walker (2003). Information needs do not, however, remain the same throughout the lifespan (Bogues, 2004; McConkey, 2003) and hence there may be the need for information in a variety of different formats targeted at specific groups of parents and family carers.

One participant in Focus group 4 suggested that some restructuring of social services might be required but acknowledged that financial constraints impact on the way in which services can be provided. An increased use of direct payments was viewed as one possible way forward:

'I am happy with the social worker but I would like social services to be re-structured, but as I said it is money again, if you have only got a limited amount and you can provide that for that you haven't got any money for anything else so you know I am not blaming them I think it is all money, a lot of it is money, but I am thinking If more people get that direct payment. Social services are not getting the money so it might be better for them to be paying what people want and they maybe can access the money a bit better, but to me that would make more sense.'
(Focus group 4)

5.3 Communication

In relation to all areas of discussion within the focus groups communication was seen to be a major issue and some examples of this have already been given above. However, a further aspect of communication is that which takes place between social services and parents and also between the parent forums and parents since both of these avenues are key to involving parents and other family carers in service development and delivery. Both of these aspects will, therefore, be considered here.

5.3.1 Communication with the Parent Forum Alliance

Comments regarding communication with the parent forum alliance were made in three focus groups and one interview. Mixed views were expressed about the role of the parents' forums. Most participants were aware that there was a forum representing parents and carers, however, not all participants received communications about their work. Several participants also indicated that there used to be correspondence but that it had now stopped. There were comments about how much impact the parents' forum could have in affecting change with one participant commenting

'There have been meetings, not many people would turn up, you would write down transport education, lack of speech therapists, lack of physiotherapists on the list and it would be the same time the next you went, nothing really happens.'
(Focus group 1)

There were also problems identified about the times of meetings and the difficulties of parents attending with participants suggesting meetings are held during the day which makes attendance difficult. It was also suggested that the groups tended to be a vehicle to let off steam with a participant suggesting:

'To be honest most of the parents' forums now are like small social groups, they just, same people going along to the group and they go along to have a good chat and moan.' (Focus group 4)

One participant suggested that this was not a new issue, but one that went back to the start of the All Wales Strategy (Welsh Office, 1983) and the messages that were given to the parents' forum then:

'Well we are promised a lot aren't we, on certain occasions, I mean going way back to the All Wales strategy (laugh) in '83, we thought the World was going to change and it was going to be wonderful, didn't really work out and I mean I went to a talk with the Parent's Forum about the new Plan that is going to be introduced, I've forgotten what it is called now.' (Interview 2)

It was also suggested that few younger parents are involved in the groups and a reason for this was put forward:

'They don't join you see, because a lot of the things that we wanted were available by the time that these young parents came along you know, it was there for them.' (Interview 2)

However, as earlier comments reveal, some of the parents and family carers with children currently undergoing the transition to adult services do have concerns regarding the availability of adult services.

5.3.2 Communication with Social Services

There were comments regarding communication with Social Services in three focus groups and one interview. There was a feeling that this should be improved along with some suggestions on how this could be achieved. There were some strong statements that suggested that Social Services were a barrier to people with a learning disability receiving services and a feeling expressed by participants that they and their offspring's needs were not listened to or addressed.

The importance of seeking the views of carers and family members was stressed:

'...they should take parents views on board as well because after all we know our young people, we've raised them we've lived with them for 20 plus years you know... we do know what's going on with their lives.' (Focus group 2)

There was acknowledgement that Social Services were seeking to consult with parents and carers:

'On a positive note, my impression is that (Unitary Authority) are actively trying to involve parent carers more in the decision making process and steering groups, they are trying to get us more involved, I certainly get invitations to meetings and if they are looking at strategy documents, they are sent through to me to comment on, the problem is because we are looking after a disabled person we don't have a lot of time, but I think they are actively trying to involve us more, probably because they are being directed to do so by Government...' (Focus group 1)

However, it was also noted that involvement in consultation processes had time implications for parents and, given that they already had enormous pressures on their time, they needed to be reassured that time invested in such activities would be worthwhile:

'I have spent afternoons looking through strategy documents commenting on them and you don't get any feedback as to whether anything has happened or whether your comments have been taken on board so they want everything one way, they want you to go to these meetings, they want you to comment but you don't get any feedback from them as to what has happened to that piece of work you have done for them.' (Focus group 1)

One participant expressed the view that Social Services had reservations about consulting with parents:

'There's no flexibility and I really do think that sometimes they're very frightened of parents they don't like involving parents.' (Focus group 2)

It was also suggested that some attempts to involve parents and carers amounted to tokenism:

'They pay lip service to us [Participants: yeah], its tokenism I think it's pure tokenism where they've got all these person-centred planning things all the money to put all of that in place we've had these leaflets that have been done that have come out, so what? If nothing is happening at ground level and our kids are not being treated fairly what the hell is the point of a piece of paper that says "you've got the respect, you've got the right to this, the right to that.' (Focus group 2)

The information received by parents was seen as being variable and this variability could depend upon who was approached for information:

'But can I say that this is nothing new, we have been saying certainly I know for the for the last ten years the parents are not kept informed, that it depends on who you talk to as to whether you find out about what you are entitled to or what and this is something we have been saying, well certainly I know for ten years.' (Focus group 1)

There was acknowledgement that there was consultation with the parent forum alliance but some anxiety about how representative such a mechanism may be with one participant suggesting this may be consultation with a small and perhaps unrepresentative group of people:

'oh well we consulted with the Parents' Forum which basically means that (gender) went to the chair of the Parents' Forum and said, 'we need to have an opinion about this' and they will consult half a dozen people sat around their table and then go back and that's the consultation' (Focus group 4)

One suggestion for improving communication was the development of a newsletter which could be sent to everyone on the local learning disability register and which could include a letter page to encourage communication. However, it was felt would still not help parents and family members who did not currently access services.

6. Conclusions and recommendations

Before drawing conclusions and making recommendations it is important to note potential limitations to the study. This research was undertaken in one unitary authority area and the number of participants was relatively small. However, it should be remembered that the aim was to provide information which could be used to assist planning in this geographical area and also that a conscious decision had been taken to undertake in depth exploration with a smaller number of participants rather than a wider survey of views. These factors need to be borne in mind when interpreting the findings and drawing conclusions. It is not possible to determine the views of those who did not take part: they could have been very satisfied with the services currently received or alternatively chose not to take part due to dissatisfaction with how things currently are. Nonetheless, as the discussion of findings has shown, many of the views expressed are reflected in the wider literature concerning the experiences of parents and carers of people with a learning disability. The findings may, therefore be viewed as contributing to this wider body of research and literature as well as providing a basis for local planning. Moreover the study sample was inclusive in that mothers, fathers and other family members supporting people with varying degrees of learning disabilities and of differing ages were involved. Some other parents and family carers indicated a willingness to take part in the study but their personal circumstances eventually precluded this. Their inclusion would have increased the number of participants but the fact that they could not take part is perhaps an indication of the pressures they face in their day to day lives.

In drawing conclusions from the findings of this study it must be noted that both positive and negative comments were received. Generally those parents and family carers of younger and less disabled family members tended to have better experiences of service provision. However, it is important to note that those who were undergoing the transition period from child to adult services expressed concerns about the effectiveness of this process and the implications for future support within adult services.

Where negative comments were forthcoming concerning specific aspects of service provision then these often reflected the wider research and literature concerning the experience of parents and family carers. This does not in any way diminish the importance of such views but rather serves to illustrate that they are common areas of concern.

Generally participants did not complain about the lack of a system but rather about the effectiveness of structures and systems which are in place or which are planned. In particular the two way nature of communication and the impact of this not working as well as it should were evident. First parents and family carers frequently complained about the lack of accessible, timely and appropriate information which was offered to them commenting instead that they often needed to be proactive in seeking out information for themselves. The role of the care manager or care coordinator would appear to be crucial here and participants noted how the variability in quality of such provision leads to variability in access to information and services. Of particular concern was the limited awareness which there appeared to be in relation to person

centred planning and direct payments: both of these developments would appear to offer much in promoting a better match between needs and support which may thus be underexploited. It is important to recognise, however, that information needs will vary across the lifecycle and hence, in seeking to address any deficits a range of approaches may be required.

The second aspect of communication is the extent to which the views of parents and family carers are sought, listened to and acted upon. Some positive comments were received in this respect but generally there was a view that channels of communication were not working as effectively as they should either at the individual or group levels. Some parents stated that they felt disillusioned since past attempts to become involved in strategic planning had not (from their perspective) been a worthwhile investment of the limited time available to them. There would thus appear to be a need for a review of mechanisms which are currently in place.

A number of comments were received concerning the limited financial resources which are available and there was an awareness of the impact that this has on both planning and service provision. However, it was of concern that a number of parents spoke of having to fight for service provision and that their fears centred upon what would happen when they were no longer in a position to support their family member. Such fears are obviously a source of much concern and stress and need, therefore, to be explored in more depth. Once again effective individual planning systems may be of assistance here.

On the basis of these conclusions the following recommendations are made:

- That greater consistency of care management / care coordination systems should be promoted. This should include ensuring that care managers/ care coordinators are in a position to provide timely, accessible and accurate information in a proactive manner.
- That wider mechanisms for providing information for parents and family carers are reviewed. This should include consideration as to how information can be provided in a variety of formats targeted to the appropriate stage of the family life cycle.
- That particular attention is given to promoting greater awareness concerning person centred planning and direct payments along with the development of support which will enable such systems to work most effectively.
- That current mechanisms for supporting young people through the process of transition to adult services be strengthened.
- That mechanisms for involving parents and family carers in strategic planning be reviewed. This should include the development of a variety of different routes which will allow for the differing demands placed upon parents and family carers and the consequent time which they have available. Most importantly it should also include mechanisms by which they can receive feedback as to the outcomes of any consultation process.
- That the importance of effective communication with parents and family carers is stressed within appropriate staff training across agencies.
- That disability awareness training be promoted for health care staff.

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Appendix One

Information Sent to Focus Group Participants

Focus Group Letter of Invitation

Dear Parent or Family Carer,

Re: Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

(Name of area) Parent Forum Alliance have asked the Unit for Development in Intellectual Disabilities (UDID) here at the School of Care Sciences, University of Glamorgan, to undertake an independent research study. This study will seek to gather the views of parents and family carers regarding current and future developments in services for people with learning disabilities. The information gathered will be used to assist in planning such developments within the local area.

We are writing to you to ask if you would be willing to take part in this study. We have not, however, been given your name or contact details since this letter has been sent out directly by (name of area) Community Services Division. We are also asking that you send your response directly to us in the envelope provided – that way Community Services will not be aware of who has agreed to take part in the study.

An information leaflet is enclosed which gives you more information about the study. We hope this will answer many of the questions you have. If, however, you have any further queries please do not hesitate to contact either myself or our Research Fellow Iliana Sardi (contact details on the information sheet).

Taking part in the study is entirely voluntary and the decision you make about participation will not affect the services you or your relative receive in any way. We hope, however, that you will feel able to contribute so that your views can inform the future planning of services.

If you are willing to take part please return the enclosed form in the envelope provided by Friday 23rd September. There is no need to put a stamp on this.

Yours sincerely,

Ruth Northway
Professor of Learning Disability Nursing

Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

You are invited to take part in the above research study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information and to request further information if required. We hope that this information sheet will answer any questions you may have.

What is the purpose of the study?

Services for people with learning disabilities have undergone many changes in recent years and further developments are planned. In this process of change it is understandable that parents and other family carers are likely to have both hopes and fears. Understanding these hopes and fears is important to those who plan and develop services. (Name of area) Parent Forum Alliance have therefore asked the School of Care Sciences at the University of Glamorgan to undertake independent research to try to determine the nature and extent of such views within the local area. This information will be gathered by means of a series of focus groups and it will then be used to help plan future developments.

What exactly is a focus group?

The purpose of a focus group is to collect information on the thoughts and feelings of a group of people on a subject of common interest. It differs from a general discussion in that it is facilitated by two researchers who will structure the discussion. This means that all important issues can be covered.

Why have I been chosen?

We are hoping to gain the views of a wide range of parents and family carers in this study. For this reason we have asked (name of area) Community Services Division to send out these letters of invitation to *all* parents and family carers of those registered with them as requiring support due to having a learning disability. This is why you have received this letter. No names or contact details have been passed to the research team.

Do I have to take part?

No. Whilst we hope that as many people as possible will take part in the study participation is voluntary. Your decision as to whether or not to take part in the study will not in any way affect the services which you or your relative receive.

What will happen next?

If you are willing to take part then we would ask that you complete and return the enclosed form in the envelope which is provided. There is no need to put a stamp on this as postage will be paid. The information on the form will be used to ensure that we invite you to the most appropriate focus group and will provide us with the necessary information to contact you. These forms will be kept securely by the research team. We will contact you either by telephone or by letter and invite you to a focus group.

What will happen at the focus group?

The group of parents and family carers will meet in a relaxed environment for not longer than an hour and a half. We will first ask you to sign a consent form confirming that you have been provided with information about the study and that you have voluntarily consented to take part. These forms will be stored securely and will not be linked in any way to information gathered from the focus groups.

The focus group will commence with the facilitators introducing the purpose of the group and covering some 'ground rules'. These ground rules deal with matters like confidentiality. The facilitators will then outline how the group will be conducted and participants will briefly introduce themselves. The facilitators will introduce the subject for discussion and will use a series of prompting questions to encourage debate. During the discussion one of the facilitators will take notes and the discussion will be tape recorded for later transcription. After approximately an hour of discussion the group will be brought to a close.

How will the information from the focus groups be used?

The focus group will be conducted in such a way as to protect anonymity and confidentiality. A tape recording will be made of each focus group for transcription purposes. Both the recording and the transcripts will be held safely by the research team and will not be shared with others. The research team will review the transcripts and will identify both areas of common concern and areas where there are different views. This analysis will be used to inform the writing of a report which will include some (anonymous) quotations of what was said in the focus groups.

This report will be submitted to (name of area) Parent Forum Alliance to assist them and local service providers with planning. However, they will not be informed who has taken part in the focus groups. It is also planned that there will be a launch event for the report later in the year. Parents and family carers will be invited to this event and we will ask at the focus group whether you would wish to attend. A summary report of the study will be made available on the UDID website.

Since changes in services for people with learning disabilities are going on throughout the United Kingdom it is likely that the findings of the study will be of interest to other people. For this reason it is planned that the findings of the study will be presented at conferences and that papers will be written for publication in journals. Once again quotations from the focus groups will be used in these presentation and papers but they will be anonymous.

Will expenses be paid?

Reasonable travel expenses will be paid for attendance at a focus group.

How can I find out more?

We are happy to discuss any queries you may have:



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Telephone: 01443 483177
Email: rnorthwa@glam.ac.uk



Iliana Sardi
School of Care Sciences
University of Glamorgan
Pontypridd
South Wales
CF37 1DL
Telephone: 01443 483189
Email: isardi@glam.ac.uk

We would like to thank you for taking the time to read this information and we hope you would be happy to participate in this important study.

Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

Thank you for your interest in taking part in the above study. To assist us in inviting you to the most appropriate focus group it would be helpful if you could just complete a few questions below regarding your family member who has a learning disability. We would then be grateful if you could complete your contact details so that we can invite you to a focus group. As explained in the information sheet provided these details will be kept securely and stored separately to any information gathered in the focus groups.

If you have more than one family member who has a learning disability please provide their details alongside the details of the first.

About your family member who has a learning disability

Are they (please tick that which applies):

Aged between 14 and 25?

Aged between 26 and 65?

Aged 66 or over?

Do you consider them to have (please tick that which applies)

A mild or moderate learning disability?

A severe or profound learning disability?

Do they have (please tick all which apply)

Physical disabilities?

Difficulties with their sight?

Difficulties with their hearing?

Please turn over

When would you prefer to attend a focus group (please tick all which apply):

During the morning?

During the afternoon?

During the evening?

Please enter your contact details:

Name:

Address:

.....

.....

.....

Telephone:

Is there any other information which you would like to give us?

.....

.....

.....

.....

Please return this form in the envelope provided (no stamp is required) by

Thank you
Ruth Northway
(01443 483177)



Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

Consent Form

Please read carefully the following questions, tick the boxes and then sign and date the form:

I have been provided with a copy of the Participant Information Sheet
[]

I have had the opportunity to ask questions about my participation []

I agree to take part in a focus group []

I agree to the focus group being tape recorded
[]

I understand that the researcher will anonymise all aspects of my participation
[]

I agree that my anonymised comments may form part of the Project Report
[]

I agree that my anonymised comments can be used in publications and conference presentations
[]

Signature.....
.....

Name
(printed).....

Date.....

Signature of Researcher.....

Appendix Two

Information Sent to Interview Participants

Interview Letter of Invitation

Dear Parent or Family Carer,

Re: Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

(Name of area) Parent Forum Alliance have asked the Unit for Development in Intellectual Disabilities (UDID) here at the School of Care Sciences, University of Glamorgan, to undertake an independent research study. This study seeks to gather the views of parents and family carers regarding current and future developments in services for people with learning disabilities. The information gathered will be used to assist in planning such developments within the local area.

We are writing to you to ask if you are willing to take part in this study. We have already undertaken some focus groups but to ensure that a wide range of views is represented we would now like to undertake some interviews. We have not been given your name or contact details since the letter has been sent out directly by (name of area) Community Services Division. We are also asking that you send your response directly to us in the envelope provided – that way no one else will know that you have taken part unless you choose to tell them.

An information leaflet is enclosed which gives you more information about the study. We hope this will answer many of the questions you have. If, however, you have any further queries please do not hesitate to contact either myself or our Research Fellow Iliana Sardi (contact details on the information sheet).

Taking part in the study is entirely voluntary and the decision you make about participation will not affect the services you or your relative receive in any way. We hope, however, that you will feel able to contribute so that your views can inform the future planning of services.

If you are willing to take part please return the enclosed form in the envelope provided by (date to be inserted). There is no need to put a stamp on this.

Yours sincerely,

Ruth Northway
Professor of Learning Disability Nursing

Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

You are invited to take part in the above research study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information and to request further information if required. We hope that this information sheet will answer any questions you may have.

What is the purpose of the study?

Services for people with learning disabilities have undergone many changes in recent years and further developments are planned. In this process of change it is understandable that parents and other family carers are likely to have both hopes and fears. Understanding these hopes and fears is important to those who plan and develop services. (Name of area) Parent Forum Alliance have therefore asked the School of Care Sciences at the University of Glamorgan to undertake independent research to try to determine the nature and extent of such views within the local area.

Why have I been chosen?

We are hoping to gain the views of a wide range of parents and family carers in this study. So far we have gathered information via a series of focus groups. However, we now wish to undertake some additional interviews to ensure that as wide a range of views as possible is included. We are therefore contacting you as a parent or family carer of someone with a learning disability who receives a service from (name of area) Community Services Division. Your name and contact details have not been given to the research team as this letter is being forwarded by (name of area).

Do I have to take part?

No. Whilst we hope that as many people as possible will take part in the study participation is voluntary. Your decision as to whether or not to take part in the study will not in any way affect the services which you or your relative receive.

What will happen next?

If you are willing to take part then we would ask that you complete and return the enclosed form in the envelope which is provided. There is no need to put a stamp on this as postage will be paid. We will contact you either by telephone or by letter and arrange a suitable time for an interview.

What will the interview involve?

A researcher will arrange to meet with you at a mutually convenient time. They will then discuss with you your views regarding some current and planned services developments. With your permission the interview will be tape recorded to allow us to transcribe and analyse it. We would anticipate that the interview would last between thirty minutes and one hour.

How will the information from the interviews be used?

Both the recording of the interview and the transcript will be held safely by the research team and will not be shared with others. The research team will review the transcripts of the interviews along with those of the focus groups and will identify both areas of common concern and areas where there are different views. This analysis will be used to inform the writing of a report which will include some (anonymous) quotations of what was said in the interviews and focus groups.

This report will be submitted to (name of area) Parent Forum Alliance to assist them and local service providers in their planning. However, they will not be informed who has taken part in the interviews. It is also planned that there will be a launch event for the report later in the year. Parents and family carers will be invited to this event and we will ask at the interview whether you would wish to attend. A summary report of the study will also be made available on the UDID website.

Since changes in services for people with learning disabilities are going on throughout the United Kingdom it is likely that the findings of the study will be of interest to other people. For this reason it is planned that the findings of the study will be presented at conferences and that papers will be written for publication in journals. Once again quotations from the interviews and focus groups will be used in these presentation and papers but they will be anonymous.

Will expenses be paid?

Reasonable travel expenses will be paid should you wish to be interviewed at a place other than your home.

How can I find out more?

We are happy to discuss any queries you may have at any time:



Professor Ruth Northway
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Email: isardi@glam.ac.uk

We would like to thank you for taking the time to read this information and we hope you would be happy to participate in this important study.

**Hopes and fears concerning service developments: a focus group study
of the views of parents and family carers.**

Thank you for your interest in taking part in the above study. To assist us in making sure that we include the views of a wide range of people with different needs it would be helpful if you could just complete a few questions below regarding your family member who has a learning disability. We would then be grateful if you could complete your contact details so that we can contact you to arrange an interview. As explained in the information sheet provided these details will be kept securely and stored separately to any information gathered in the interview.

If you have more than one family member who has a learning disability please provide their details alongside the details of the first.

About your family member who has a learning disability

Are they (please tick that which applies):

Aged between 14 and 25?

Aged between 16 and 65?

Aged 66 or over?

Do you consider them to have (please tick that which applies)

A mild or moderate learning disability?

A severe or profound learning disability?

Do they have (please tick all which apply)

Physical disabilities?

Difficulties with their sight?

Difficulties with their hearing?

Please turn over

When would you be available to be interviewed (please tick all which apply):

During the morning?

During the afternoon?

During the evening?

Please enter your contact details:

Name:

Address:

.....

.....

.....

Telephone:

Is there any other information which you would like to give us?

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.....

Please return this form in the envelope provided (no stamp is required) by
(date to be inserted)

Thank you
Ruth Northway
(01443 483177)



Hopes and fears concerning service developments: a focus group study of the views of parents and family carers.

Consent Form

Please read carefully the following questions, tick the boxes and then sign and date the form:

I have been provided with a copy of the Participant Information Sheet
[]

I have had the opportunity to ask questions about my participation []

I agree to take part in an interview
[]

I agree to the interview being tape recorded []

I understand that the researcher will anonymise all aspects of my participation
[]

I agree that my anonymised comment may form part of the Project Report
[]

I agree that my anonymised comments can be used in publications and in conference presentations
[]

Signature.....

Name
(printed).....

Date.....

Signature of Researcher.....

