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**A Scoping Project of Members of Cardiff and the Vale
Parents Federation: Developing a Carers' Perspective**



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Executive Summary

Background

Cardiff and the Vale Parents Federation is a charity run by parents and informal carers of people with learning disabilities in Cardiff and the Vale of Glamorgan. They have a growing membership which currently stands at over 640 members. The organisation is funded from a variety of sources including Local Authorities (through the All Wales Strategy). It is through the Parents Federation that the views of parents and unpaid carers are officially shared with Local Authorities, Health Bodies, and the Voluntary Sector in Cardiff and the Vale of Glamorgan. The School of Care Sciences (now the Faculty of Health, Sport and Science), University of Glamorgan was commissioned by the Federation to undertake this research.

Aims and objectives

The primary aim of the project was to develop a carers' perspective on what it means to care for a person with learning disabilities and to gain carers' opinions on a range of topics relevant to their caring role. The study gathered information from the members of Cardiff and the Vale Parent Federation. Amongst the many issues addressed by the study were Access to Health Care Professionals, Services and Information; Respite Care; Education, Early Transition and Adult Transition; Work, Leisure and Accommodation and Current Issues of Importance.

Methods

The data for this study was collected in two stages. The first stage asked members of Cardiff and the Vale Parents Federation to complete a questionnaire. This was followed by the second stage where members were invited to take part in one of two focus groups with an additional electronic voting round. A mixed methodology approach was adopted in order to increase the quality and scope of the study data. The semi-structured questionnaire yielded both qualitative and quantitative data. The focus group took a similar approach by scoping members' views, after which electronic voting technology was used to obtain general group consensus.

Key findings

Accessing healthcare services, information and to healthcare professionals

Carers reported being well able to access general practice and dentistry services but other professional services, such as speech and language services, were seen as far less accessible. The need to fight and shout in order to receive appropriate services was a clear message from carers. In many instances there was evidence that information was not readily forthcoming. Parents and carers felt frustrated and angry at the general lack of health and social care information and access to some services.

Respite

The need for a flexible range of respite provision was evident from the studies findings, coupled with a need to increase the amount and quality of respite available. Parents and carers wanted a better understanding or definition of the term respite care; a common definition shared by both service users and service providers.

Education and transition

It is clear from both the questionnaire results and the focus group interviews showed that carers had a preference for special school environments in terms of their school

of choice for the person they cared for. In relation to planning for early and adult transition the study found inadequacies in both the level of information available to carers and the general lack of planning and support offered.

Work, rest and play

Carers expressed concerns about the low level of employment opportunities currently on offer to people with learning disabilities, acknowledging that the full potential of people with learning disabilities was not being met.

In terms of accommodation carers expressed a preference for a small home attached to parents/carers main home so that the person with learning disabilities could be still be best supported in their quest for independent living.

The study found a disturbing level of people with learning disabilities who did not take part in any leisure activities and this was seen as having profound implications for their quality of life.

Current issues of concern to carers

It was evident from the study findings that when carers were asked to identify their current issues or concerns they wanted reassurance that there would be a stable and secure package of care available for the person with learning disabilities when they were no-longer able to care themselves. The federation membership has an aging population who were clearly anxious about their ability to care in the longer term. A number of other issues were highlighted such as access, quality and quantity of respite care, suitable educational provision and access to health and social care information.

Conclusion and recommendations

Accessing healthcare services, information and to healthcare professionals

Many challenges lie ahead for the Federation and its members. In many instances there was evidence that information was not readily forthcoming. Most importantly, professionals who support carers must have sufficient knowledge and information of available services and pass this information on in a more structured way than currently occurs, as a matter of course to all carers. There should be greater service user input and collaborative working in relation to accessing information and service provision generally.

The Federation should work with statutory organisations to develop and improve how information is communicated and disseminated to all carers as a matter of course. A centrally active point of contact for health and social care information and advice is recommended. The Federation should escalate the service it currently provides to carers. It should advertise this service more widely to carers and follow up all enquires made to the centre from carers for help, advice and information in order to validate the assistance given and feed their findings back into improving the services provided to carers.

General Practitioners can be considered as gatekeepers to carers wishing to access health and social care services. There is a need for specialist practitioners such as the Community Support Teams to ensure that GPs are clear on the role and function of teams.

Respite

More research is required in relation to the quality, quantity and flexibility of respite care; as is the need for a shared definition. The Federation should undertake work with other interested parties (including statutory and voluntary bodies) to establish clear definitions of what constitutes respite care and clear minimum criteria covering the range of respite provision. This should include eligibility, duration and flexibility of service. Carers need to be aware of the respite provision available so that they are fully able to utilise respite provision.

Education and transition

Carers want greater choice, flexibility and support in terms of the type of educational establishment available. They believed their views are not currently being given sufficient consideration when school placements are being decided. Efforts should be made to improve this situation.

Again, the quality and quantity of information provided to carers regarding transition plans (early and adult) should be improved to ensure that parents and carers both understand, and can make a meaningful contribution to, the transition process. The Federation should explore how carers can be better and more fully supported during transition periods which often produce additional stress and anxiety to both carers and the people they care for.

Work, rest and play

Without doubt, people with learning disabilities are still not having their full potential acknowledged in the work environment. The Federation should lobby for closer collaborative working between Carers and those responsible for educational provision, organisations such as Career Wales and local employees in an attempt to address this important issue.

Further research should be undertaken to extrapolate and examine data about the large group of people with learning disabilities who do not partake of any leisure activities; this should specifically measure the quality of life of those concerned and address potentially harmful psychological and physiological related issues.

Carers expressed an accommodation preference for a small home attached to parents/carers main home. Cost analysis should be undertaken to assess the financial implications of adapting or adding to the family home against alternative form of accommodation currently on offer.

Current issues of concern to carers

Carers identified a number of issues currently causing them concern; such as access, quality and quantity of respite care, suitable educational provision and access to health and social care information. They also wanted to know there would be a stable, secure and caring support available to the person with learning disabilities when they were no-longer able to care themselves. Clearly, the risk of parent and carer stress and burnout is exacerbated when carers have unaddressed worries and concerns, the Federation should therefore engage as many members as possible in exploring how their current concerns can be addressed as matter of urgency.

BACKGROUND

Cardiff and the Vale Parents Federation is a charity set up and run by parents and informal carers of people with learning disabilities in Cardiff and the Vale of Glamorgan. They have a growing membership which currently stands at over 640 members. The organisation is funded from a variety of sources including Local Authorities (through the All Wales Strategy). It is through the Parents Federation that the views of parents and unpaid carers are officially shared with Local Authorities, Health Bodies, and the Voluntary Sector in Cardiff and the Vale of Glamorgan. They can also put parents and carers in contact with other parents with similar experiences, who are happy to share their knowledge and the ways they have been able to make progress.

Project Aim

The primary objective of the project was to gather information from the members of Cardiff and the Vale Parent Federation on a wide number of issues relevant to their work as a 'carer' organisation, and to the well-being of their members and the people their members care for. The School of Care Sciences (now the Faculty of Health, Sport and Science), University of Glamorgan was commissioned by the Federation to undertake this research. In light of the complex nature of the scope of the project, a number of composite papers were written and together form the complete account of the project undertakings and findings. These include sectional reports on:

- 1- Access to Health Care Professionals, Services and Information
- 2- Respite
- 3- Education, Early Transition and Adult Transition
- 4- Work, Leisure & Accommodation
- 5- Current Issues of Importance- for Parent/Carers

INTRODUCTION

There is a growing body of literature which explores the perceptions of parents and carers regarding both the services their offspring (person they care for) receive, and the dynamics of the caring role. For a detailed review of these issues the reader is directed to the recent research compiled by the Unit for Development in Intellectual Disability, University of Glamorgan. Their report, entitled 'Hopes and Fears' (Northway et al., 2006), formed the backdrop on which the current research was conducted.

Carers play a very significant role in the lives of people with learning disabilities and there is a growing emphasis on the importance of carers' and parents' views and participation in the planning and delivery of services on both formal and informal levels. The All Wales Strategy (Welsh Office, 1983) indicated that the development of services for people with learning disabilities should "involve representatives and their families in the planning and management of services for people with learning disabilities" (paragraph 6.3.4 (ii)). The current study set out to scope the views of parents and carers across a diverse range of issues that impact on their ability to care effectively for someone with learning disabilities.

Access to Services and Information

An essential component of a carer's role is being able to access health and social care services as well as high quality information for both themselves and the person they care for. It is recognised that carers themselves double their risk of being permanently disabled because of the demands of their caring role (Carers Scotland 2007). It is also accepted that people with a learning disability are more likely to have unmet health needs than the general population and paradoxically this client group is less likely to access primary care services (including those of the General Practitioner). People with a learning disability are likely to suffer similar health problems as the general population but the range and frequency may be greater. We know for example that this client group is more likely to present with epilepsy, dental disease, mental health needs and sensory deficits (Welsh Health Survey 1995). The Disability Rights Commission (2006) report that people with a learning disability risk having two and a half times more health problems than the non disabled population. In addition to this we also know that some people with learning disabilities are more likely to present with specific health problems. For example people with Down Syndrome may present with congenital health disease, leukaemia, obesity, hyperthyroidism and Alzheimer's disease.

Although people with learning disabilities have greater health needs, many of these needs go unrecognised. Howells (1986), and Wilson and Haire, (1990) identified very high rates of unidentified health needs in this population, and this pattern has continued in studies through to the current date (Barr et al., 1999, Kerr et al, 2005). Further, Samele et al (2006) found that people with learning disabilities who did not have a previously identified health need were also less likely to receive screening tests from their General Practitioner (GP) surgery in relation to blood pressure testing, cholesterol testing, urine analysis and weight.

In exploring why people with a learning disability may be less likely to use primary health services the following reasons have been suggested: poor physical access, inappropriate waiting areas, staff attitudes (including those of reception staff) and poor knowledge of the needs of the client group by nursing staff and GPs hindering communication (Prowrie, 2003).

Recently, health checks in Wales have become an enhanced service provided by GPs. This requires general practices in Wales to identify people with a learning disability known to the Local Authority Social Services Department and invite them for an annual health check. However, these checks do not have to be administered by the GP and many are delivered by primary care staff and community learning disability nurses. The current research should provide an indication of the carers' ability to access a range of professional services, including health services.

Respite Care

Caring can, and often does, have a direct influence on a person's physical and psychological health and well being. This can include financial costs such as a lowering of earning potential, reduction in actual income and the increased costs of caring. The National Strategy for Carers (Department of Health, 1999) considered three key elements: support, information and care for the carer. This publication highlighted the need for short term breaks for carers in order to improve their well-being and therefore their ability to continue in the caring role.

Undoubtedly, carers recognise the importance of 'respite care', not only for themselves (and the saving incurred by the state) but for the people they care for. Whilst a number of models of provision exist for obtaining respite care services, surprisingly little is written about the different types, availability, suitability or relative value of these respite care services. However, the under provision by Local Authorities of respite services has long been suspected, with many carers expressing a desire for more flexible, varied and frequent services (Northway et al., 2006).

In very recent review of the literature exploring the potential barriers to the uptake of respite care in older people services, Shaw (in press) highlights that a number of factors influence access to respite. These include guilt on behalf of the carer, a strong desire to continue the caring role and for some carers this was described as an obligation. Other factors influencing the uptake of respite include a lack of knowledge or awareness of the range of respite services available and concerns regarding the perceived quality of provision. Quality anxieties related to concerns regarding staff competence and staffing levels.

In a follow up to its initial respite report entitled 'Breaking Point' (Mencap, 2003), Mencap (2006) reports that despite lobbying and awareness raising there had been little improvement to access to respite services for parents and carers. Families report they are still failing to receive appropriate respite services. In its report Mencap produces a charter which suggests that families have the right to breaks; and that these should be of good quality and should be regular, reliable and frequent. It also indicates that these breaks should be enjoyable for the person with a learning disability. Finally they suggest that families should be provided up front with

information regarding services available and should have both a carer's assessment and a short break action plan.

Catherall and Iphofen (2006) also highlight the benefits of respite care to families. They provide examples of families who have to plan daily life for their disabled offspring reporting that the only opportunity for spontaneity with their other siblings comes during periods of respite.

The current study therefore aims to identify the type, quality and relative levels of satisfaction with current respite service provision, while at the same time obtain information about future respite carer expectations.

Education & Transition

Education

The 1970 Education Act and subsequent legislation states that children with special educational needs (SEN) should attend mainstream schools if their needs can be met there; an objective that was emphasised again in the 1996 Education Act (Department of Education, 1970, 1996), which strengthens the rights of pupils with statements of SEN to attend mainstream education.

The promoting of children with learning disabilities into mainstream education is based not only on the rights of children to be included in mainstream education, but also on the provision that inclusive education is more effective (Lindsay, 2007). However, Cooney et al. (2006) reported that the type of school attended had no effect on the children's identities, future outlook or negative treatment by others. While OFSTED (2004) reported less favourably on the quality of provision and support which children with disabilities receive in mainstream schools. Thus, suggesting that mainstream schools are not necessarily more effective than special schools for the education of children in learning disabilities. In fact Mittler (2007) reported that recently there has been political pressure on the Government to review its commitment to inclusive education and to place a moratorium on the closure of special schools.

The study reported here aims to identify the type of schools attended as well as the parents' and carers' opinions of the current school types available for people with learning disabilities.

Early Transition

The move from childhood into adolescence, around the time a child leaves primary school and enters secondary education, can be traumatic for any child, especially one with learning disabilities. It is recognised that planning should begin in early childhood and continue throughout the many transitions which people make through life (Learning Disability Implementation Advisory Group, 2006). However, the transition from child to adult services (when a young person leaves school around the age of 16) is seen as the time when the most significant changes are likely to occur. This is also recognised as a stressful time for any family and is reflected in the current research on transition, with a dearth of research into early transition while the main research focus had been on adult transition instead.

The current study aims to make a start to address filling the gap in the literature on early transition by asking parents and carers if their child (or the person they cared for) received an early transition plan, and whether they were offered sufficient information, help and advice during this time.

Adult Transition

When young people with learning disabilities leave school and approach adulthood, this can again be a time of high anxiety. They not only have to cope with the ordinary challenges of growing up and deciding on a future path (i.e. whether to attend college or go into employment, or to move out of home), but they also have to deal with the challenges that come with moving from child to adult social support and health services. It is therefore highly important that during this time an effective transition plan is carried out in order to minimise any potential stress and uncertainty for the young person and their family. The Department of Health's 2001 White Paper (DoH, 2001) emphasises the importance of a seamless transition between child and adult services with their objective to "ensure continuity of care and support for the young person and their family" (DoH, 2001, p.4).

However, Hudson (2006) found that the transition from adolescence to adulthood for people with a learning disability has not been handled well. He stated that, despite the Government's acknowledgment of the problem and their enthusiasm to address it, any "progress seems to be frustratingly limited" (p.47). Heslop et al. (2002) provided evidence of inadequate adult transition with their findings that, despite legislation and guidance, a large number of young people were leaving school either without a transition plan or with an ineffective one in which they had no involvement in, did not cover topics or key issues that they considered important, made no difference to what happened after they left school or did not provide information about future possibilities.

Heslop and Abbott (2007) found that parents identified four main issues that, if achieved, would lead to a smoother transition and a more satisfactory outcome. These were: being well-connected with key professionals, being proactive, having sufficient information and good forward planning. The European Agency for Development in Special Needs Education (2006) agrees that transition must be based upon the direct involvement and co-operation of all parties concerned in order to ensure a seamless transition between child and adult services. They also believe that transition must ensure that the young person is placed at the centre of the process by listening to what they, and their family, see as important for their future.

Tarleton and Ward's (2005) study emphasises Heslop and Abbott's (2007) finding of the importance of having sufficient information during transition. They reported that parents wanted basic information such as '*what is transition*', '*what services are available locally*', '*what rights and entitlements exist*', and '*whether there are specialist transition workers*'.

Finally, with regard to the findings by Heslop and Abbott's (2007) on good forward planning, the Department of Health (2005) stated that, in order to achieve a satisfactory transition, a young person's future plans need to be in place long before they leave school. However, as already discussed, this is not always the case and in

reality many children end up leaving school with no transition plan and no idea of what they intend to do in the future (Heslop et al., 2002). The Learning Disability Implementation Advisory Group (2006) emphasised the importance of transition planning in the development of longer term outcomes. The Group states that “inadequate planning and provision during childhood can have adverse consequences not only for the individual but also for the level of service support required throughout adulthood” (LDIAG, 2006, p.16).

The study reported here aims to explore parents’ and carers’ views on adult transition- including whether, parents and carers should be involved in planning for adult transition, whether they were offered support and given enough information at this time, and whether the whole process met their expectations.

Work, Accommodation & Leisure

Work

An overriding objective of the Government’s English White Paper ‘*Valuing People: A New Strategy for Learning Disability for the 21st Century*’ (Department of Health, 2001), is to encourage and assist people with learning disabilities in their quest to gain employment. Of course employment carries with it the additional benefits of promoting individual self-esteem, skills, social integration and acceptability. However, it has been well documented that individuals with learning disabilities often experience difficulties trying to gain and retain employment. Very few people with learning disabilities are in paid employment. The study reported here aims to identify the number of people with learning disabilities within the Federation who were currently engaged in work related activities, the types of work they were involved in and whether they received payment in return for the work undertaken.

Accommodation

Valuing individuals extends to valuing their choices regarding where and how they want to live. Predominantly, housing choice has long referred to residential care provision. This is thought to have inhibited the type and quality of alternative accommodation currently available to people with learning disabilities. The current study reported here aims to identify the types of accommodation carers deemed appropriate for the person they cared for.

Leisure

Of equal importance to work and accommodation is leisure. Leisure after all is an important human activity providing relaxation, pleasure and self-satisfaction. Access to leisure activities impacts on a person’s psychological, physiological, cognitive, spiritual and social domains (Driver et al, 1991). Taking part in leisure activities not only enriches the lives of people with learning disabilities, it can also help to keep ensure their health and happiness. Therefore involvement in leisure activities is rewarding for both the person with learning disabilities and the person caring for them. The study reported here aims to identify the types of leisure activities people with learning disabilities were involved in and the types of leisure activities parent/carers wanted to see available in the future.

Current Issues of Importance

This study also sought to identify issues that parents and carers currently viewed as important to their caring role, with the intent to encompass all those aspects that impinge upon quality and continuity of care delivered to the person with learning disabilities. By specifically scoping carers' '*current issues of importance*' the researchers wanted to ensure that the project topics were relevant and valid while at the same time securing the most up to date issues of concern. The majority of work in the learning disabilities area is based on pre-existing themes and this was seen as a way of allowing carers to have their say and input directly into the learning disability research. There is a scarcity of previous work in this area (Northway et al., 2006) and therefore it was anticipated that the study's findings would direct future research aiming to voice carer current concerns.

METHOD

Design

The data for this study was collected in two stages. The first stage asked members of Cardiff and the Vale Parents Federation to complete a questionnaire. This was followed by the second stage where members were invited to take part in one of two focus groups. A mixed methodology approach was adopted in order to increase the quality and scope of the study data. The semi-structured questionnaire yielded both qualitative and quantitative data. And the focus group took a similar approach, scoping members' views after which electronic voting technology was used to obtain general group consensus.

Questionnaire Design

The questionnaire was designed in line with the service demands of Cardiff and the Vale Parents Federation members and those they care for. The topics included in the questionnaire also included issues relevant in the literature. A pilot of the questionnaire was undertaken with the Federation's full committee. Following this and peer review feedback, alterations were made to the design and content of the questionnaire.

The aim of the questionnaire was to provide information on the perceived quality and scope of the services available to parents/carers (and the people they care for).

In order to achieve this aim the areas explored in the questionnaire were:

- Access to Health Care Services
- Respite
- Education
- Early Transitions
- Transition to Adulthood
- Employment
- Leisure and Recreation
- Accommodation
- Current Issues of Importance

The questionnaire consisted of closed and multiple choice quantitative questions . In addition, some questions were formulated to provide space for participants to make qualitative comments. Not all sections were relevant to all parents/carers- detailed instructions helped participants to complete the relevant sections.

Sample

The population of 647 members of Cardiff and the Vale Parents Federation (made up of parents and carers) were sent a copy of the questionnaire (Appendix 1) in July 2006, along with a letter giving details of the study (Appendix 2). Members were also given the opportunity to express an interest in attending a focus group. Initially 126 questionnaires (19% of the population) were completed and returned. In September 2006 repeat questionnaires were sent out to non-respondents, which

increased the response rate to 23% (151 questionnaires). Tables 1 to 11 below provide information relevant to the sample's demographic make-up and that of the people they cared for.

Questionnaire- Parent/Carer's Demographic Details

The number of carers who completed the questionnaire was 151 and included both parents and family carers. Carers' age and gender can be seen in Tables 1 and 2 below. The majority of carers were women (82%), while 75% were in the older age ranges- 44% were over the age of 55, and nearly 1 in 5 had caring responsibilities despite being over the legal retirement age. Moreover, 22% of carers were themselves disabled (Table 3) and 16% had poor mental or physical health (Table 4).

Age range	Number of Carers	Percentage of Carers
25-34 years of age	4	2.6
35-44 years of age	32	21.2
45-54 years of age	47	31.1
55-64 years of age	37	24.5
over 64 years of age	29	19.2
Missing	2	1.3

Table 1 – Carers' Age (n=151)

Gender	Number of Carers	Percentage of Carers
Male	26	17.2
Female	124	82.1
Missing	1	0.7

Table 2 – Carers' Gender (n=151)

Disability	Number of Carers	Percentage of Carers
No Disability	117	78.0
Physical Disability	14	9.3
Mental Disability	10	6.7
Other	9	6.0
Missing	1	.7

Table 3 – Disability amongst carers (n=151)

Health Status	Number of Carers	Percentage of Carers
In Good Health	126	83.4
Not in Good Health	24	15.9
Missing	1	0.7

Table 4 – Carers' Health Status (n=151)

Nature of caring role	Number of Carers	Percentage of Carers
Full Time	126	83.4
Part Time	24	15.9
Missing	1	0.7

Table 5 – Nature of caring role (n=151)

Focus Group- Parent/Carer’s Demographic Details

Age range	Number of Carers
25-34 years of age	1
35-44 years of age	1
45-54 years of age	2
55-64 years of age	3
over 64 years of age	2
Missing	6

Table 6 – Carers’ Age – focus group (n=15)

Gender	Number of Carers
Male	5
Female	10

Table 7 – Carers’ Gender - focus group (n=15)

Demographic details – those being cared for

Table 8 below provides information concerning the age of the person being cared for; ages ranged from 4 years to 67 years, with 20% being under the age of 12, and a further 28% being in their ‘teenage’ years. Sixty-five percent of those being cared for were male, and 34% were female (Table 9). Parents/carers indicated their perception of the range and type of disability experienced by the person they care for, 52% have severe/profound difficulties and 44% have mild to moderate disabilities (Table 10). While the types of disabilities experienced (Table 11) were, in the majority of cases, multiple in nature (66% n=151).

Age range	Number of people	Percentage
4-11 years	31	20.5
12-19 years	43	28.4
20-35 years	44	29.1
35-44 years	17	11.2
46-67 years	13	8.6
Missing	3	1.9

Table 8 - Age of those being cared for (n=151)

Gender	Number of people	Percentage
Male	98	64.9
Female	51	33.8
Missing	2	1.3

Table 9 - Gender of those being cared for (n=151)

Degree of disability	Number of people	Percentage
Mild/moderate	66	43.7
Severe/profound	79	52.3
Unknown or missing	6	3.9

Table 10 - Degree of disability those being cared for (n=151)

Type of disability	Number of people	Percentage
Learning	38	25.2
Mental Health	4	2.6
Physical	7	4.6
Multiple	99	65.6
Missing	3	2.0

Table 11 - Type of disability those being cared for (n=151)

Questionnaire Analysis

Members of the evaluation team took part in the analysis of the qualitative data using a comparative method. Themes were identified and grouped according to the number and type of response. Questionnaire data was analysed using Statistical Package Social Science for Windows (SPSSFW) version 14, seeking response and percentage frequencies.

Focus Groups

The data collected from the questionnaires was used to draw up a focus group interview schedule (Appendix 3). In addition, questions and related responses specific to each interview topic were input into Teamworker® (Appendix 4). Teamworker® is an electronic voting system that comprises of individual cordless handsets linked to a base computer. Once specific questions are input into the software, participants are able to communicate responses back to the computer, via correlated numbers on their handsets (<http://www.teamworker.com/index.html>).

Participants posted back a focus group attendance letter (sent out with the questionnaire) to request attendance at a focus group. These participants were then contacted and asked to attend a choice of two focus groups, at different times and locations. Six participants attended focus group one, while nine attended the other; both focus groups were held in November 2006.

Upon arrival at the focus groups, participants were provided with an information sheet and a consent form to sign. They were also given the opportunity to ask questions. All participants were provided with a Teamworker® handset. All participants agreed to be tape recorded. The focus group process and electronic voting system was explained, as were issues of confidentiality.

Both focus groups were conducted by two experienced members of the research team. Each topic of discussion (Appendix 3) was followed with a related question and voting session via the Teamworker® handsets. The results of each voting round were displayed, in the form of bar charts, on a overhead screen. This feedback provided significant stimuli for further discussion, which often resulted in explanation of any contrary opinions and preferences.

At the end of each focus group participants were given a further opportunity to ask questions and given details of when a report of the findings would be available for them to read. Travel expense claims forms were also available.

Focus Group Analysis

Following transcription of focus group tapes, the data was then analysed using NVivo (version two) qualitative analysis software (Miles and Huberman, 1994). Transcripts were read by two members of the research team. Emerging themes were identified and the transcripts were coded according to identified categories and themes. Inter-rater reliability was promoted by comparing the analysis undertaken by the two team members and agreement reached.

Ethical Considerations

Ethical approval to conduct this study was obtained from both the University of Glamorgan Ethics Board and Cardiff and the Vale Parents Federation.

All information sent to members emphasised that participation in the study was completely voluntary and that not taking part would not affect any of the services the potential participants receive. All participants were given full information sheets regarding their participation in the study. All data were anonymised and participants were asked to complete a consent form prior to taking part in the focus group (Appendix 5). With regard to the quantitative section of the study, consent was presumed on the basis of a completed questionnaire. All participants were given the opportunity to ask questions regarding any aspects of the study and their involvement.

It was recognised that the subject of the focus group may be upsetting for some participants to talk about. The research team was available after the focus groups to discuss any issues that may have caused upset. In addition, all participants were members of Cardiff and the Vale Parent Federation and therefore had access to, and knowledge of, available support if necessary.

FINDINGS

As already discussed, data gathered from the questionnaires and focus groups were analysed and coded using Statistical Package Social Science for Windows (SPSSFW) version 14 and NVivo software package.

Given the explorative nature of the study, descriptive statistics were applied to the questionnaire data and are presented in tables and figures below. Categories for discussion were generated from the focus groups and the themes that emerged from the questionnaire data. An initial qualitative analysis led to the development of categories and themes. These categories and themes were re analysed to ensure internal consistency.

The descriptive data from the questionnaire and emerging category and themes from the focus groups are presented in the tables below along with quotes taken directly from the questionnaire and focus group discussions. These are included verbatim (to reflect what was actually said). Finally, the data from the normative electronic voting sessions is also presented.

Access to Services and Information

The emerging categories and themes gathered from the two focus groups are presented in Table 12 below.

Category	Theme	Sub-theme
Services and information available	Sources of support	<i>Parents and peer support, Professionals, Other</i>
	Relationships with key workers	<i>Positive experiences, Turnover of staff, Inconsistency, Power differences</i>
	Need to shout	<i>Fighting for what you need, Shouting for what you need</i>
	Emotional support	<i>Availability, Family and peer support</i>

Table 12 - Categories and themes arose from the two focus groups.

Questionnaire Data

An essential component of a carer's role is being able to access health and social care services as well as high quality information for both themselves and the person they care for. This study revealed that the vast majority of carers were well able to access their general practice and dentistry services. This was borne out in the focus group electronic voting, where carers overwhelmingly choose their general practice as best meeting the health care needs of the person they care for. However, approximately two thirds of those respondents that wanted to access either occupational, counselling and speech and language therapists or a psychologist, found it either very difficult or impossible to do so. Similarly, half of all respondents that wanted to access a

paediatrician, dietician, health visitor, social worker, physiotherapist or hospital inpatient services were also finding it difficult or impossible.

Service	Very easy to access	Easy to access	Difficult to access	Impossible to access	Not applicable
General practice (GP) n = 149	42	88	17	0	2
Dentist n = 148	30	83	26	5	4
Hospital outpatient services n = 143	8	54	33	3	45
Hospital inpatient services n = 141	5	15	18	6	97
Physiotherapist n = 145	8	22	28	13	74
Speech & Language therapist n = 144	6	17	35	25	61
Occupational therapist n = 145	4	22	37	17	65
Counselling therapist n = 143	1	5	9	18	110
Psychologist n = 144	2	17	20	16	89
Paediatrician n = 142	6	29	22	4	81
Dietician n = 142	1	19	24	6	92
Community nurse n = 142	14	18	14	11	85
Health visitor n = 145	5	21	13	10	96
Social worker n = 145	10	45	44	13	33

Table 13 – Access to healthcare services and access to professionals

Similarly difficulties were identified by carers attempting to access healthcare equipment or to change or upgrade equipment. Over two thirds of carers who had

attempted to access, change or upgrade healthcare equipment found the process difficult or impossible.

Service	Very easy to access	Easy to access	Difficult to access	Impossible to access	Not applicable
Healthcare Equipment n = 147	4	15	36	11	81
Changing or upgrading healthcare Equipment n = 148	1	11	32	13	91

Table 14 – Changing or upgrading healthcare equipment

The type of support a carer has available impacts on their ability to access health and social care services, professionals and information. Only half of the carers surveyed had a social worker, indicating that a large number of carers lack this additional means of support when finding it difficult or impossible to access services.

Type of support	Number of respondents
Key worker	8
Social worker	65
Care manager	9
Community nurse	6
More than one form of named support	23
No named support	27
Not applicable	9

Table 15 – Type of named support carers currently receive n = 147

Figures from the survey also indicated that many carers had not received information about the different types of services and support systems that could have a potential impact, in a positive way, on their ability to care for a person with learning disabilities. Although information concerning benefit entitlement (two thirds of respondents) and carers' assessment (approximately half of all respondents) were the two areas that came out best, the vast majority of carers had not received information about important issues such as direct payments, independent living, care management and disabled facility grants.

Type of information	'No', information given	'Yes', information given
Person Centred Planning n = 130	101	29
Unified Assessment n = 125	101	24
Benefit Entitlement n= 124	42	82
Direct Payments n = 118	57	61
Future Planning Wills & Trusts n = 115	81	34
Independent Living Fund n = 124	83	41
Disabled Facility Grant n = 120	85	35
Care Management n = 121	96	25
Carers Assessment n = 130	69	61

Table 16 – Access to information

Focus Group Analysis

Access to GPs

Within the questionnaire survey there was a consensus that access to GPs was good or excellent. This finding was explored within the focus groups and the questionnaire findings were supported.

Participants suggested that they felt that their GP recognised their needs as a carer, one participant commented:

“On a recent visit just for a check up it all comes up on a screen all the history and background, I had the impression they realised I was a carer. Now I don't know whether that's been highlighted somewhere ... in their notes that this person is a carer and if that's general or whether it's just they've got that from somewhere”
(Focus group 2).

In the discussion GPs were described as excellent, amazing and very kind. However, there was a feeling that parents and carers 'identified' which GP would be most supportive in the practice or that it was necessary to change GPs until you found a supportive one.

One participant commented:

“Like that lady (said) they weren’t all excellent, we moved three or four times but the people we’ve got now I can’t fault them” (Focus group 2).

However, there was a feeling that the GP service was not always as positive as it is now and significant improvements have occurred. Reasons why the GP service was thought to have improved and reached a high standard were offered. These included a perception of changes in medical training with more contact with and content about the needs of people with a learning disability. There was also thought that there has been a change in ‘policy’ with greater expectations placed on GPs to meet the needs of people with a learning disability and their carers.

“And I feel the doctors have been told by the government or somebody to take particular note of people with learning disabilities” (Focus group 2).

Professions allied to medicine

The majority of difficulties highlighted were regarding access to professionals allied to medicine related to speech and language therapists. There was seen to be a dearth of available staff making access (both historically and currently) difficult.

One participant stated:

“We’d have one for a few days and then they would leave, they were very thin on the ground in the end, there were no speech therapists” (Focus group 2).

There was also a comment suggesting that speech and language therapy was most needed when the child was very young:

“You can’t wait until they are forty, it’s ridiculous and also the only reason she gets that half an hour is because (the therapist) is based in school” (Focus group 2).

A parent/carer gave an insight into the situation from their point of view and expressed the feeling of being resigned to the situation:

“... I remember when my son had a statement there was a point there whilst he desperately needed speech therapy there were no speech therapist. It was not pointed out that we had a right to pursue that and we went along blindly taking people to their word on the assumption that we understand that it is a lack of resources and that’s how it is” (Focus Group 1).

One positive comment was received in relation to speech and language with a participant indicating that their offspring had received a good service:

“We had a choice when (name) at first went a school for speech therapy which was quite the correct place we felt and it did him a lot of good” (Focus group 1).

Emotional support

One of the areas explored within the focus groups was that of emotional support and access to counselling services for parents and carers. Most participants had not accessed, or were not aware of, any counselling services which may available:

“Because I just cope on my own I think well I don’t really need it but when I do need them I do ask for help, it’s not out there” (Focus group 2).

Another less positive example was provided which paints an historical picture of ‘just getting on with it’. A participant stated:

“I don’t know if my situation is different you know ... my daughter and I can remember being told once that you chose this, get on with it” (Focus group 2).

There was also a suggestion within a focus group that the ‘generation gap’ may be a factor with older parents not expecting support, however younger parents and carers coming through may expect this:

“Dare I say I’m thinking that obviously you are a lot younger than the rest of us and I do think that makes a difference I think you know we’re perhaps more the generation who thought we had to get on with it so we do” (Focus group 2).

The feeling of differing expectations based on the generation of the carer was reinforced by another comment in the same focus group. This participant indicated that some elderly carers may not seek support until a crisis occurs:

“Elderly parents in their eighties and nineties and still looking after them who inevitably you know won’t be able to take advantage of all the things because of their own problems, unless they’ve got someone who can help them and very often these people will say they don’t want help until a crisis comes along” (Focus group 2).

Other examples of ongoing emotional support was said to come from a young wives’ group, other family members and a parents’ support group in the local school. One participant suggested this had been a great help:

“When I joined the school they’ve got a parents support group and that was fantastic.... The stories, they share, even down to services like we were saying before, the information I’ve got just from those eight people is incredible” (Focus group 2).

Being able to talk to peers was thought to be important and to learn from other parents who had similar experiences. In addition to this a parent/carer suggested that MENCAP was also able to provide some support.

Fighting and shouting

Fighting and shouting for services presented at several stages through the two focus group interviews. There was a definite view expressed by participants that the person who shouts loudest was most likely to receive appropriate services. Those who may be less assertive in coming forward were felt to be left behind and interventions may only take place as a result of a crisis.

In a frank exchange one parent contrasted the differing approaches of parents suggesting the parent who 'shouts' receives the service:

“Well I have two people in mind when I answer this question, both mothers um the one is very neurotic, cries all the time you know, how we all feel basically, very frustrated but she gets on the phone and does it. Because she won't shut up until they give it to her and you know again I don't know whether that's right or wrong but it's that seems to be the process. You know if you're on the phone and you are nagging you get it” (Focus group 2).

One candidate expressed the feeling that rather than be given necessary information you had to battle for it, suggesting:

“I think that it is probably a key word, is the word the lady used is “fight” rather than “this is yours by right, here is the information that will help you” you have to fight every step of the way for whatever you can gain” (Focus group 1).

A further participant shared some candid information provided some years' earlier by a professional which she suggested had stood her in good stead:

“So I said no, look you live in (name of geographical area) you've got a car you're comfortable and you think you'll manage. Okay, you can now but I tell you now if you don't start shouting for what you want, you will get left behind. Mrs Smith down the road will get everything, you've got to go with what is going for you and it was the best advice ever and that was the beginning of having a form of respite for my daughter and you know it sounded sort of quite sort of cruel but she was right and it was just saying you know, stick up for yourself really” (Focus group 2).

A strong statement was made by a participant in the same focus group who felt that having to fight was a long term event suggesting:

“It’s really as everybody knows, you are fighting the whole of the lives of your, you know you never stop, I’m sorry I don’t want to sound depressing because I mean we have a great time with her a lot of the time” (Focus group 2).

This was felt to be particularly debilitating and frustrating and can be clarified with a comment suggesting:

“And you are just fighting, fighting, fighting, there is no energy left and you cannot, the last thing you want to do is phone people up” (Focus group 2).

Electronic Voting

Question	Response range	Focus group 1	Focus group 2
Who do you find is most useful when accessing information in your capacity as a carer?	1. Key Worker/ Professionals	-	2
	2. School	-	-
	3. Day Centre	-	1
	4. C & V Parents Federation	-	1
	5. Other support groups	5	5
	6. Internet	1	-
Who best helps you meet the health needs of the person you care for?	1. General Practice	-	8
	2. Key Worker	-	-
	3. Social Worker	-	-
	4. Care Manager	-	-
	5. Community Nurse	-	-

Table 17 – Focus group responses relevant to accessing information and support with health needs.

Which one is the most important to you?	1. Accessing service provision	3
	2. Independence/ Quality of life	2
	3. Information and Support	1
	4. Respite care	1
	5. Who will care when we can't?	1
	6. Educational provision	1

Table 18 – Focus group issues of importance

Respite Care

The emerging categories and themes gathered from the two focus groups are presented in Table 19.

Category	Theme	Sub-theme
Respite care	Definitions	<i>For whom, How long, Significance for carer, Equity of access</i>

Table 19 – Categories and Themes that arose from the two focus groups

Questionnaire Data

Respite care and support can and often does make a difference to the lives of the person caring and the person being cared for, however, the results of the questionnaire clearly show that the vast majority of carers either did not receive respite or were limited to less than one day a month. Only 65 carers (43% n=151) received what they considered to be ‘respite’ support and of this group just over one quarter, (26%), were in the small minority of receiving more than one weekend a month.

Respite support	Number of people	Percentage
<i>Receiving respite support</i>	65	43.0
<i>Not receiving respite support</i>	85	56.3
Missing	1	.7

Table 20 - Respite support (n=151)

Amount of respite support received per month	Number of people	Percentage
Less than one day per	14	21.5
Over night	24	36.9
One weekend	10	15.3
One week	9	13.8
More than one week	3	4.6
Missing data	5	7.6

Table 21 – Amount of respite support received per month (n = 65)

When carers were asked ‘what type of respite support would you like?’ their expectations reflected their current unmet need in terms of respite. Responses were grouped accordingly and set out in Table 22. These results indicate that quality and diversity in terms of respite are two essential determinates for carers and the people they care for.

Type of respite requested by carers
'Babysitter'/'Childminder' for rare nights/ trips out
Overnight
Weekend
More than a week per month
Respite were qualified staff are employed
Local supported respite house, with good well trained staff, including nursing input
Carer to support child
Short breaks away
Adult placement
Respite for a few days
Foster link
Weekend breaks
Independent holiday
Holiday activities
Places to allow interaction with other disabled children
Hotel type accommodation
Centres open at weekends for activities
Overnight stays with carers

Table 22 – Type of respite requested by carers

Focus Group Analysis

Respite care was discussed in both focus groups. The discussions were split into two sections. One focused on the issue of definitions of respite and the second tended to discuss equity of access.

In discussing respite, the issue was raised regarding who was the principal beneficiary of respite or, who respite was for. One participant suggested: *“One of the confusing things is – is respite care for the person you are looking after or respite for the carer”*. (Focus Group 2) The feeling was expressed that professionals looked at respite from the perspective of the client whilst focus group participants felt it covered both parties. One participant suggested:

“I feel that respite to us is a period of time when our daughter is away having a great time with new people, friends in the house she meets up with and having different experiences” (Focus group 2).

However, a contrasting vision of respite was provided by a participant who suggested that:

“I have just taken advantage two weeks which enabled my husband I to go to America without any worry whatsoever. And, um I was really concerned because I thought he would never stay there but he had a whale of a time” (Focus Group 1).

A second point which was not clear from the questionnaire survey results was what constitutes respite care in relation to duration. The participants of the focus group had differing views on this. Several participants thought that respite care included 'day service' provision whilst the majority felt an overnight stay should be included in order for the break to be considered respite. In relation to the former, one participant suggested:

“So another confusing thing is some people get day service for a few hours, sometimes it's very fragmented but that is counted as respite care I believe” (Focus group 2).

A second participant felt that this definition of respite was questionable suggesting that:

“He leaves at half past twelve and is back by three, its not much of a respite you know” (Focus group 2).

As indicated, most participants suggested an overnight stay was necessary for the 'break' to be considered as respite. This was summed up by a participant in focus group 1 who suggested:

“Longer than that! I think my understanding would be not day care, it might be but it is not a real respite (a few women agreeing) you might to out and do a bit of shopping, certainly it would start with an overnight or probably two nights minimum, a week would be heaven wouldn't it” (Focus group 1).

The importance to carers of having respite care was discussed. Comments were expressed suggesting that it allowed participants to *“Just to be ordinary people”* (Focus group 2) and *“having time to lead what we would call a normal life”* (Focus group 2).

Parents and carers discussed what they felt were professionals' unrealistic expectations for carers during periods of respite. One participant commented:

“I would like a complete and utter break from my daughter, preferably overnight, I don't know why it is, some time ago a social worker said to me because my daughter was as you just said out of the house for x hours, you go off and enjoy yourself..... why as carers can we unwind like the strike of a clock and everywhere else wants days to wind down, I don't understand why we are that different, in that sense” (Focus group 2).

Another participant questioned professionals' understanding of individuals' circumstances stating:

“I think what professionals don't recognise is the fact that the natural progression is that you have a child, they grow

up, they leave home and for us that never happens” (Focus group 2).

Equity of access was an issue that was discussed in both focus groups. One participant suggesting that there was an overly long waiting list:

“in my case(name) has been on the waiting list for respite for two years, just over two years and two months” (Focus group 2).

There was also a feeling that the authorities had criteria for individuals accessing respite but no clear of understanding what these criteria may be. A participant commented:

“Some people get more, obviously it is led by criteria as we know. Single parents, divorced parents whatever. (others agree). There are also the huge problems now we found whereas if the person’s got medical conditions that’s now precluding them from a lot of respite opportunities, we were only able to access a hospice” (Focus group 1).

This was reinforced by a participant in the same group who commented:

“.....my friend who has a child with learning disability and she had been on the list 14 years in the (names geographical area) and hasn’t had any respite until the last couple of months. And yet some of her friends have had it from the age of three. I really don’t know how sometimes how they actually decide to make these decisions” (Focus group 1).

There was a feeling expressed that information may not be given regarding respite owing to the lack of available provision. There was also a feeling that, once an individual is receiving respite then the position changes and further access to continuing respite is much easier. A participant commented:

“....it does help with some people that they get on the list early. And then it is sort of re-cycled you know and you find that they are going for a week and a fortnight regularly, I think it is quite difficult to get on if you’re not on already” (Focus group 1).

Electronic Voting

Question <i>Are you happy with the current respite provision that you receive?</i>	‘Yes’	‘No’
Number of responses Focus Group 2	2	7
Number of responses Focus Group 1	3	3

Table 23 – responses to question: Are you happy with the current respite provision that you receive?

Question (Focus Group 2 only) <i>Which of the following is the most important issue for you regarding respite?</i>		
	1. Payment	-
	2. Flexibility	4
	3. Choice of venue	2
	4. Length of stay	3

Table 24 – responses to question: Which of the following is the most important issue for you regarding respite?

Education & Transition

The emerging categories and themes gathered from the two focus groups are presented in Table 25 below.

Education	Choice of school	<i>Mainstream Vs. Special</i>
Transition	Quality of experience	<i>Negative experiences, Lack of services, What makes good transition</i>

Table 25 – Categories and Themes that arose from the two focus groups

Questionnaire Data

Education

Carers were asked to indicate whether the person they cared for, with a learning disability, was currently being educated or had been educated in the last five years. Ninety-five carers responded to this question (Table 26). Within this group 14 children or young adults were in special units attached to a mainstream school and only 12 children were in the mainstream school system (Table 27). The majority (55-58% n = 95) were in special schools while 62% of respondents said they had not been offered any choice in terms of where the person they cared for might be educated (Table 28).

Educational status of person with learning disability	Number of responses n = 95	Percentage
In full time education	72	75%
Part-time education	2	2%
In education in the last five years	21	23%

Table 26 – Educational status of person being cared for

Educational establishment of person with learning disability	Number of responses n = 95	Percentage
Mainstream school	12	12%
Special unit within mainstream school	14	15%
Special school	55	58%
Further education college	3	3%
Residential	2	2%
University	2	2%
Other	7	7%

Table 27 - Educational establishment attended by person being cared for

Education Choice	Number of respondents n = 94	Percentage
“Yes”, offered choice of educational establishment	21	22%
“No”, not offered choice of educational establishment	58	62%
Unsure	15	16%

Table 28 – Educational Choice

Carers were also asked to indicate their thoughts on the three most traditional types of educational establishment i.e. mainstream, unit within mainstream and special schools. The most popular educational establishment for carers was the special school system (Table 31) with 70% (n = 92) suggesting that they preferred this type of schooling for the person they cared for. Mainstream schooling was the least popular (Table 29) with only 26% of carers suggesting they liked this type of schooling.

Mainstream school		
Educational preference	Number of respondents n = 85	Percentage
Strongly like	6	7%
Like	16	19%
Neither like or dislike	35	41%
Dislike	13	15%
Strongly Dislike	15	18%

Table 29 – Carers’ thoughts on mainstream schools

Unit within mainstream school		
Educational preference	Number of respondents n = 85	Percentage
Strongly like	14	16%
Like	31	35%
Neither like or dislike	31	35%
Dislike	4	4%
Strongly Dislike	8	9%

Table 30 – Carers’ thoughts on unit within mainstream schools

Special School		
Educational preference	Number of respondents n = 92	Percentage
Strongly like	32	35%
Like	32	35%
Neither like or dislike	20	22%
Dislike	7	7%
<i>Strongly Dislike</i>	1	1%

Table 31 – Carers’ thoughts on special schools

Transition

When carers were asked about transition, both ‘early years’ and ‘adult’, nearly 60% (n = 47) of carers had not been offered an early transition plan (Table 32) and nearly half of those who felt they should have received information about adult transitions had also not been given the information they required (Table 33).

Question: <i>“Have you been offered an early transition plan?”</i>	Number of responses n = 47	Percentage
Yes	15	40%
No	32	60%

Table 32 – Early transition plans

Question: “Were you involved in planning of adult transition plan?”	Number of responses n = 60	Percentage
Yes	33	68.3
No	27	31.7

Table 33 – Information about adult transition plans

Focus Group Analysis

Education

The debate regarding the provision of education focused on mainstream versus special educational provision. Within the focus group interviews, a range of views were expressed, however the majority of participants suggested that, although they supported the principle of mainstream provision, they felt that special educational settings were the most appropriate provision for their offspring.

This was represented by the comment from a participant who suggested:

“I wanted him in mainstream but it just wasn’t appropriate for him, he couldn’t cope” (Focus group 1).

Support was also an issue with a parent suggesting:

“I think with the right support but I don’t think they get the right support and it would be like you there are pros and cons” (Focus group 2).

Transition

Few positive examples of transition were provided. The majority of participants who commented on the transition process highlighted failings. There was also a feeling that there was a significant reduction of services available following the move to adulthood.

In relation to the transition process, one participant commented on the lack of joined up work between professionals leading to confusion:

“Absolutely diabolical. The last year had been probably ... one of the worst years of our lives, because none of the agencies seem to want to work together. Try to get them to have a meeting whether it be the colleges or your special needs co-ordinator from the school that you’re leaving, your social worker, there’s a huge number of people you have to deal with and a young person is often overwhelmed by the numbers of people that they have to deal with they still don’t seem to know exactly what’s available” (Focus group 1).

There was also a feeling that the people were fitted into services rather than services being provided to meet needs. A participant commented:

“Yes but they are fitting the adult to their needs not the adult or young person needs. They are not addressing their needs; you will go to a day centre” (Focus group 2).

This participant went on to say:

“I think if they were to listen and to take into account the need of the young person rather than trying to fit them into a mould you know sort of you are going to a day centre, you will do this you will do that” (Focus group 2).

There was also a sentiment expressed that there was a feeling of crisis management in relation to transition. A lack of forward planning was suggested with a participant suggesting:

“Like forward planning because they know these people are coming up to a certain age and they are going to have a change of services, we’ve been fighting this, they never seem to know what are they going to do now you know at

the last minute. They've had all the information on ages and disabilities” (Focus group 2).

A further comment received suggested that the information provided was limited and, despite the large numbers of professionals involved in the process, there was a lack of opportunities available post eighteen:

“All you do is spend your time having meetings and as you say, they don't seem to want to give you information that they've got anyway, which is very strange. It seems they get to 18 and that's it. They don't seem to know what to do with them after the age of 18” (Focus group 1).

The lack of health support was noted following the child leaving children's services - adult services were described as becoming fragmented:

“You're coming out of education, you're also, we found, coming out of the medical side, so you no longer have one paediatrician so if your young person has several medical problems you're now dealing with umpteen consultants who never speak to each other. So you're suddenly ending up with visiting, in a period of a year, maybe twenty different agencies and people” (Focus group1).

Electronic Voting

Question	Response criterion	Focus group one	Focus group two
<i>Which of the following do you feel is the most important in transition?</i>	1. Choice	1	3
	2. Support from professionals	-	2
	3. Life skills & PD	1	3
	4. Information	4	-

Table 34 – Responses to question: ‘Which of the following issues do you feel is most important in transition?’

Work, Accommodation & Leisure

The emerging categories and themes gathered from the two focus groups are presented in Table 35 below.

Category	Theme	Sub-theme
Work and Leisure	Meaningful jobs	<i>Support, Positive experiences,</i>
	Leisure	<i>Accessibility, Finances,</i>

Table 35 – Categories and Themes that arose from the two focus groups

Due to time constraints the issue of accommodation was only briefly discussed during the course of focus group one and not at all during the second focus group. Accommodation did not, therefore, produce a focus group category or sub-theme. Time constraints also prevented any questions on work, accommodation or leisure from being asked via the electronic voting equipment.

Questionnaire Data

Work

There were 71 people in the study population with learning disabilities aged 20 to 65. When parent/carers were asked whether the person they cared for took part in any work related activities, either paid or unpaid, just over one third said they did (26 people). Fifteen people were said to work in either a shop or café style environment, with only one person working outdoors and two working in an office type setting. More importantly, the majority (69.2%) worked for two days a week or less and well under half of those working were in paid employment (10 people, n =26).

Question: Does the person you care for take part in a work related activity?	Number of Learning Disabled People	Percentage
Yes - takes part in work related activities	26	36.6
No - does not take part in work related activities	45	63.4

Table 36 – number of learning disabled people involved in a work related activity (n = 71)

Paid or unpaid work	Number of people	Percentage
Paid	10	38.5
Unpaid	16	61.5

Table 37 - whether in paid or unpaid work (n=26)

Work location	Number of people	Percentage
Shop	11	42.3
Cafe	4	15.3
Office	2	7.6
Outdoors	1	3.8
Other	8	30.7

Table 38 - type of work related activity (n=26)

Number of days worked per week	Number of People	Percentage
half a day	5	19.2
1 day	8	30.8
2 days	5	19.2
3 days	2	7.7
3 1/2 days	1	3.8
4 days	2	7.7
5 days	2	7.7
6 days	1	3.8

Table 39 - Number of days worked per week (n=26)

Accommodation

Carers were asked to provide information about the kind of living accommodation they would like to see available for the person they cared for. A number of carers choose not to answer this section of the questionnaire and this may have reflected those caring for younger children, who have not yet considered future issues such a accommodation. Carers were provided with a comprehensive list of eight accommodation models, and they were asked to indicate their accommodation preferences as either, favourable, unfavourable or no opinion:

- Where a person has their own legal tenancy in a home shared with a small group of people
- Own home attached to existing family home
- Living with parents or relatives
- Village communities
- Core and cluster
- Adult fostering/Supported lodgings
- Warden assisted
- Living alone with own tenancy

Shared home with own legal tenancy	No of carers	Percentage
Favourable	60	52.2
No Opinion	37	32.2
Unfavourable	18	15.7

Table 40 – Carers s response to accommodation style ‘shared home with own legal tenancy’ (n=115)

Living with parents or relative	No of carers	Percentage
Favourable	72	60.0
No Opinion	17	14.2
Unfavourable	31	25.8

Table 41 – Carers’ response to accommodation style ‘living with parents or relative’ (n= 120)

Small home attached to families own home	No of carers	Percentage
Favourable	74	64.9
No Opinion	18	15.8
Unfavourable	22	19.3

Table 42 – Carers’ response to accommodation style ‘small home attached to families own home’ (n= 114)

Village Communities	No of carers	Percentage
Favourable	49	41.9
No Opinion	27	23.1
Unfavourable	41	35.0

Table 43 – Carers’ response to accommodation style ‘village communities’ (n= 117)

Core & Cluster	No of carers	Percentage
Favourable	65	55.1
No Opinion	38	32.2
Unfavourable	15	12.7

Table 44 – Carers’ response to accommodation style ‘core & cluster’ (n= 118)

Warden Assisted	No of carers	Percentage
Favourable	55	48.2
No Opinion	31	27.2
Unfavourable	28	24.6

Table 45 – Carers’ response to accommodation style ‘warden assisted’ (n= 114)

Adult fostering/supported lodgings	No of carers	Percentage
Favourable	36	31.0
No Opinion	45	38.8
Unfavourable	35	30.2

Table 46 – Carers’ response to accommodation style ‘adult fostering/supported lodgings’ (n= 116)

Living alone with own tenancy	No of carers	Percentage
Favourable	22	19.1
No Opinion	25	21.7
Unfavourable	68	59.1

Table 47 – Carers response to accommodation style ‘living alone with own tenancy’ (n= 115)

The preferred style of accommodation amongst the parents and carers who responded to the accommodation section of the questionnaire was a small home attached to families own home (64.9%, n =114). This was followed closely by ‘living with parents or relatives (60.0%, n = 120). The least favoured accommodation style was ‘living alone with own tenancy’ (19.1% n= 115), with 59.1% of parents and carers stating this form of accommodation was unfavourable.

Leisure

Parents and carers were also asked “what type of leisure activity they would like to see available for the person they cared for?” Responses were grouped accordingly and set out in Table 48 below. These findings indicated that quality and diversity was considered to be of paramount importance. Current levels of leisure activity were also measured and this revealed that 30.5% of people with learning disabilities do not take part in any activity that parents or carers think of as leisure related and of those that do 63.4% pay to do so (n =104).

<i>Type of recreational and leisure activities carers would like the person they care for to take part in</i>
Arranged visits to: beach, shopping, film studios
Art/photography
Bowling
Canoeing
Cinema
Cricket
Cycling
Dance Classes
Disco
Eating out
Exercise type activities
Football
Gymnastics
Horse riding
Hydrotherapy
Judo
Music activities
Outdoor pursuits
Play schemes
Rock climbing

Running, athletics
Scouts
Soft play: swings, slides, interactive play, visually stimulating play
Swimming
Teen Scheme/Youth Club
Tennis
Theatre, drama
Things to do where you can interaction with others
Trampolining
Walking
Weekend & Midweek Holidays play schemes

Table 48 – Type of leisure activities requested by carers

Types of leisure activity person with learning disabilities currently takes part in	Number of people	Percentage
Sports	56	37.1
Arts & crafts	6	4.0
Clubs	19	12.6
Other	23	15.2
No leisure activities	46	30.5
Missing	1	.7

Table 49 – Types of leisure activity person with learning disabilities currently takes part in (n=151)

Leisure activities	Number of people	Percentage
Paid	66	63.4
Unpaid	26	25.0
Pay for some but not all	7	6.7
Missing	5	4.0

Table 50 – Paid or unpaid leisure activity (n=104)

Focus Group Analysis

Work

The discussions surrounding work and leisure predominantly occurred in focus group one. Employment was briefly discussed with a participant suggesting that having a job was extremely important to their off spring, however this person suggested that employment was very hard to find and even when people were in employment there continued to be stressors:

“..they can start a job but you can’t guarantee that they will always be able to do that job and going in and out is extremely difficult and quite stressful for people. And I think a lot of parents opt for the not work option because they know the trauma that will come if it doesn’t go right” (Focus group 1).

This participant also indicated that they had previously even paid an organisation to allow the relative to work there.

Leisure

It was noted from the questionnaire survey that almost two thirds of the respondents responded that they took no part in any leisure related activities. There were good examples given of the support and positive experiences gained through the participation in leisure activities.

One participant praised a care manager who had facilitated access to leisure, but then indicated a recurring theme throughout the interviews. The fear that the individual was looking to move to a new post and the anxiety this causes. The fear was expressed that the leisure opportunities may cease:

“... she takes him to McDonalds...for lunch ...But that’s all due to this care manager getting in touch with (Organisation) she has been brilliant. But then she says that she is going to look for other work” (Focus group 1).

Several participants suggested that leisure could have a positive impact on independence and personal communication skills with a participant suggesting:

“Once they’ve made that break they don’t want to be going around with their parents all the time do they” (Focus group 1).

Communication was also seen to be a benefit of participation in leisure with a participant commenting:

“especially so to the ones who probably aren’t able to access some of the vocational things. You know, um they learn and they get confidence and they can learn to talk better and communicate better if they are with people” (Focus group 1).

This was supported by the comment of a parent who indicated:

“(name) was quite, she reads well and she used to bury herself in her books but I mean now she is hardly reads she is out ‘hanging out’ as she calls it” (Focus group 1).

However, on a less positive note a participant in the group whilst sharing the opinion of the benefits of leisure felt that it lacked the status of ‘vocational’ schemes and was grossly under funded. This participant suggested:

“with leisure being a means to developing social skills and confidence, but speaking of somebody in our capacity

whose involved in leisure based organisations, getting funding to support leisure is near impossible. It is a dirty word. If it's vocational, but you can train people to the ends of the earth with more certificates than they know what to do with but you can't help somebody to develop an interest of their own which they become good at as far as their concerned" (Focus group 1).

Current Issues of Importance

The emerging categories and themes gathered from the two focus groups are presented in Table 51 below.

Current issues of importance		<i>Continuity, When I'm no longer around, Planned service provision, Financial concerns</i>
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Table 51 - Category and Themes that arose from the two focus groups

Questionnaire Data

During the survey, carers were asked to identify issues that were currently of importance in their role as a carer. In order to acknowledge that some carers might have more than one issue that was currently of concern to them, carers were able to identify and prioritise their first, second and third issue of importance. This data was categorised by three members of the research team and revealed that 'help accessing services and professional support' was the key issue of importance. This was followed closely by 'respite care', 'independence/quality of life' and 'who will care when we can't?' (Table 52).

Issue identified as important	Number of respondents 1st choice n = 114	Number of respondents 2nd choice n = 64	Number of respondents 3rd choice n = 20
Help accessing service provision/professional support	26 (23%)	10 (16%)	3 (15%)
Respite care	24 (21%)	6 (9%)	1 (5%)
Independence/quality of life (for person with learning disability)	19 (16%)	15 (23%)	1 (5%)
Who will care when we can't?	19 (16%)	5 (8%)	1 (5%)
Other	17 (15%)	23 (36%)	13 (65%)
Problems with educational provision	9 (8%)	5 (8%)	1 (5%)

Table 52 - Issues identify as currently being of importance to parents/ carers

Focus Group Analysis

When discussing issues that were currently important to parents and carers four key themes emerged: 'continuity', 'when I'm no longer around', 'planned service provision' and 'financial concerns'. Respite care was also highlighted; however, this has been discussed in some depth in an earlier section.

One participant stressed that although change was inevitable the lack of continuity could be very frustrating:

“One of our concerns is some form of stability in knowing what’s going to happen but of course you can’t if everything is changing all the time which it does seem to be doing. What is available is changing all the time and you’ve got no idea how long these things will last, which makes it really difficult” (Focus group 2).

In relation to the issue of what happens ‘when I’m no longer around’ one participant stated:

“What happens to her when I can’t look after her?” (Focus group 2).

In response to this another participant replied:

“Yes I feel like that too, I want somewhere that’s going to love her and look after her the same as I do” (Focus group 2).

A note of despair for the future was expressed by a participant who indicated how they feared getting older and having to rely on services for support:

“But even so you know, I think services are in my view so awful that I fear getting old, I know that as I get older I’m not going to be able to care and what is going to happen to her?” (Focus group 2).

The fear of inappropriate placements was raised, in particular the use of older peoples’ homes for younger people with learning disabilities:

“I think the old peoples’ home looms because this is what has happened to some people. They’ve been put in old peoples’ homes, you know young people until they can find somewhere to um, and that really frightens me” (Focus group 2).

Two comments summed up the discussion within the group with a participant indicating that what parents and carers want is for their offspring to be settled:

“We need to know that they are happy out there, that they are secure and safe and happy” (Focus group 2).

Whilst a further participant gave a less optimistic summing up indicating:

“Terrifies me, the thought of the future to be truthful” (Focus group 2).

Linked to the subject of planned services ‘security of tenure’ was seen to be an important issue as was ‘living in a good area’. One participant suggested that:

“I think secure tenancy and even with I’d like to see a stake in that, even a small stake so that they can’t be moved around easily with good support and in a good environmental area. Because the tendency is to I think to build these places in run down area” (Focus group 2).

Another issue raised at this point was difficulty in accessing residential services. A participant suggested her daughter would enjoy living in supported housing but access to the service was problematic:

“I know the sort of thing that my daughter would probably enjoy because she loves respite, she likes being with other people. ...and you know they seem to put your name down on a list but the list is a hundred and fifty four people at the moment and where are they going to get the money to find homes for a hundred and fifty four people already on the waiting list?” (Focus group 2).

This participant highlighted the level of frustration felt and also pointed to the pressures on parents and carers in ensuring that their off-spring are settled:

“We would rather see her settled in something and honestly it’s awful to say but when you are dead and gone you won’t know what is happening and all you can do is what you can while you’re alive” (Focus group 2).

This sentiment was supported by a participant in the other focus group who indicated:

“We’re trying to get [name] into supportive housing now because we’re concerned that if we leave it to long it may be too much of an adjustment for her to make” (Focus group 1).

In relation to funding both ‘security’ and ‘continuity’ were again concerns. Not only for the present time but also for when the parents and carers could no longer carry out the caring role. One participant indicated:

“Stability of that situation and security and we’re all think as we’re getting older, What’s going to happen, in my case to my daughter, when we die, we’re not here? There needs to be a system in place where we don’t have to worry about that. It is easy to say I admit that” (Focus group 1).

This was supported by a participant in the same focus group who stated:

“We just know that she wants to be funded in something for the rest of her life” (Focus group 1).

Electronic Voting

<i>Which of the following is the most important to you?</i>	1. Accessing service provision	3
	2. Independence/ Quality of life	2
	3. Information and Support	1
	4. Respite care	1
	5. Who will care when we can't?	1
	6. Educational provision	1

Table 53 – Focus group 2 responses to question “which of the following is most important to you?”(electronic voting was only used with Focus group two for this question).

DISCUSSION

From the responses received from carers via the questionnaire survey, focus group interview responses and the votes cast using the electronic voting technology a number of important issues were identified and discussed below.

Access to information and services

An essential component of a carer's role is being able to access health and social care services as well as high quality information for both themselves and the person they care for. The study found that General Practitioner (GP) services (along with that of the dentistry) were seen by carers as the easiest health or social care services to access, in terms of both professional care and provision of healthcare information. Of itself, it can be argued that this response was unsurprising as GP's have long been described (and described themselves) as the gatekeepers to health and social care (British Journal of Nursing, 2002). However, what is heartening within this study is the high satisfaction rate expressed with the GP service carers received and a clear expression of a perceived improvement in the service provided. It is noted that participants discussed being prepared to change their GPs until a good quality service provider was found but this remains a positive finding.

The study highlighted a less positive picture in relation to professionals allied to medicine, with speech and language therapists singled out (within the focus group interviews) as particularly difficult to access at the appropriate age of the individual who required the service. From the questionnaire results approximately two thirds of carers that wanted to access either occupational, counselling and speech and language therapists or a psychologist, found it either very difficult or impossible to do so. Similarly, half of all respondents that wanted to access a paediatrician, dietician, health visitor, social worker, physiotherapist or hospital inpatient services were also finding it difficult or impossible.

A similarly negative picture presented itself in relation to the accessing, changing or upgrading of health care equipment. More than two thirds of participants responding to the questionnaire survey reported that this was difficult or impossible. This may be linked to the fact that a number of respondents suggested that they did not have access to a named support professional who may be in a position to facilitate access. However, of those how did have named support the issue staff turn over was also seen as having a negative impact on service provision and information.

The quality and quantity of information provided to carers about differing aspects of health and social care services was again said to be non existent or inadequate – with the exception of GP's. More than two thirds of respondents indicated they had no information regarding Care Management, Person Centred Planning or the process of Unified Assessment. This raises issues about how such information is disseminated and links back to the comment from a focus group participant who suggested that information frequently had to be 'prized out' of professionals rather than being shared as a means of facilitating seamless and supported care.

When the study looked at the emotional support that parents and carers were offered, most had never considered, or were not aware, of any counselling services which may have been available to them. Also, feelings were expressed that perhaps a generation gap existed with older parents and carers not expecting a great deal of psychological or counselling support and that this may be perceived as more of an issue for younger parents. When asked where parents and carers went to receive support the focus group participants discussed peer and family groups such as young wives, family members, parents support groups and school. There was an overall feeling amongst members that other carers were a good source of information.

This perceived generation gap may be significant in relation to some older carers. Older carers, it was suggested may not seek support until a crisis occurs or they are at breaking point. This disparity amongst carers concurs with previous work (Bowley and McGlaughlin, 2007). This is particularly relevant and important consideration as almost twenty percent of carers who responded to the questionnaire survey were over 64 years of age. Further, looking to the future, nearly half of the parents and carers who responded were over the age of 55 and will thus be at or over the 'retirement' age within the next 10 years.

The need to fight and shout in order to receive appropriate services was a clear message received from the focus group interviews. This finding was identified in other literature (Northway et.al. 2006). The consequences of needing to fight and shout may well mean that less assertive parents and carers or aging carers are less able in the current climate to access services for their learning disabled off spring.

This situation might well be improved by the provision of a system of meaningful information, disseminated to ensure that parents and carers are aware of entitlements and to close disparity gaps amongst carers. Equally, professionals who support carers must have sufficient knowledge and information of available services to identify and meet carers needs. This study found evidence of parents and carers feeling frustrated and angry regarding the provision of health and social care services and the risk of parent and carer burnout cannot and should not be under-estimated.

Conclusion and recommendations

Many challenges lie ahead for the Federation and its members. In many instances there was evidence that health and social care information was not readily forthcoming. Most importantly, professionals who support carers must have sufficient knowledge and information of available services and pass this information on in a more structured way than currently occurs, as a matter of course to all carers. There should be greater service user input and collaborative working in relation to accessing information and service provision to ensure improvements in this area.

In addition, General Practitioners can be considered as gatekeepers to carers wishing to access health and social care services. There is a need for specialist practitioners such as the Community Support Teams to ensure that GPs are clear on the role and function of teams.

The Federation should work with statutory organisations and its membership to develop and improve how information is communicated and disseminated to all carers as a matter of course. A centrally active point of contact for health and social

care information and advice to carers is recommended. The Federation should escalate the service it currently provides to carers. It should advertise this service more widely and follow up all enquires made to the centre from carers for help, advice and information in order to validate the assistance given and feed findings back into service improvement and provision.

Respite Care

The amount of respite received

Respite care and support can and often does make a difference to the lives of the person caring and the person being cared for. Within the questionnaire survey 56% of respondents receive no respite care and more than 80% report received one day or less per month. It must be recognised that this notion of unmet need is complex; whilst there may be an agreement from parents and carers and professionals that respite is required, if the parent or service user does not deem the accommodation suitable or have concerns regarding the quality of the service then there may be a decision not to use it (Sines 1999, Mencap 2006). The need for both a flexible range of respite provision and an increase in the amount and quality of respite provision available was evident from the studies findings. This research and other studies clearly indicate more research is required in relation to the quality, quantity and flexibility of respite care.

One of the key factors to emerge from the study was the lack of a clear understanding or definition of respite care held by parents and carers. There was confusion as to whether the term respite care related to a break during the day (whilst the person they cared for attended a day time activity), or if an overnight stay was required for a break to be considered as respite. This issue was discussed at some length in one focus groups and the overwhelming consensus reached was that respite provision should be at least overnight. This sentiment was forcefully expressed by a focus group respondent who provided the comment that “*why as carers are we expected to unwind at the stroke of a clock while others take days?*” These comments related to a discussion based around professionals who on returning from holiday reported that it took days to relax before they could start to enjoy the benefits of being on holiday while in contrast, following an overnight or short respite break the professional view was that parents and carers should feel immediately refreshed and revived.

Who is respite for?

Cotterill et al (1997) pointed out that respite has traditionally been thought of as a break for parents and carers; however they have also indicated that wider views of respite emphasise the importance of the break for the service user. McConkey (2005) suggests that respite is used most by people with high dependency needs, service users with hyperactivity or other behavioural challenges, parents who were considered to be excessively stressed and single parent families. Excessive stress was shown to be a predictor of respite uptake and this equates with finding within this and previous studies (Northway et al. 2006) with those shouting the loudest most likely to receive respite support. However, this applies only to those parents and carers who are able to articulate their level of anxiety but leaves those who are less vocal with potentially inequitable provision and at greater risk of stress and family breakdown.

Equity and fairness

The present study concurs with other research looking at equity and a fair distribution of respite care. McConkey (2005) suggested in his study that of the families identified as having a high need for respite only a quarter were receiving it. He reported that only 34% of carers within his sample had access to respite overnight. The settings used for these breaks included residential settings, holiday settings or another person's home.

In contrast nearly 10% of families with a low need received respite and almost a third of families with a high need did not receive any. Again, a similar finding was outlined by the current research. In the focus group interviews parents and carers argued that there appears to be no set criteria to access respite. That respite care was far too 'hit and miss' and this was in part due to a lack of information available to parents, carers and service users regarding the provision of respite care, (supporting the Mencap, 2006 recommendation in this area). Sentiments expressed in a focus group also highlighted this issue, "*if you don't know what it is, or what's out there, how are you supposed to get it?*" Parents and carers also noted a long wait to receive the service, but paradoxically, once in receipt of respite services it tended to continue to be offered irrespective of any change in circumstances or level of need.

Conclusion and recommendations

More research is required in relation to the quality, quantity and flexibility of respite care; as is the need to establish a shared definition. The Federation should work with other interested parties (including statutory and voluntary bodies) to obtain clear definitions of what constitutes respite care and clear minimum criteria covering the range of respite provision. This should include eligibility, duration and flexibility of service. Carers need to be aware of the respite provision available so that they are fully able to utilise respite provision.

1. There should be clear definitions of what constitutes respite care and clear minimum criteria covering the range of respite provision and include eligibility, duration and flexibility of service
2. Parents carers and service users need to be given this information, so that they are fully aware of the respite provision available to them and are therefore better able to utilise respite care provision
3. Parents carers and service users should be made aware of the minimum standards that should be expected from using respite care

Education & Transition

Education

It is clear from both the questionnaire results and the focus group interviews that the respondents believed that special school environments were the schools of choice. This directly contradicts current policy in this area; the 1970 Education Act (Department of Education, 1970) states that children with special educational needs should attend mainstream schools, while the 1996 Education Act (Department of Education, 1996) strengthens the rights of pupils with statements of SEN to attend mainstream education. Our findings are supported by the 2004 OFSTED report that

with respect to the quality of provision and support which children with disabilities receive, mainstream schools were seen as less favourable to special schools. Whilst within the focus group interviews there was recognition of the philosophy underpinning moves to a model of mainstream education, this was not seen as the most appropriate setting for their individual child's education. This was often seen as mainly due to the perceived difficulties in accessing the necessary support to facilitate adequate education in this setting.

Transition

In relation to early and adult transition planning the results were disappointing. Nearly two thirds of questionnaire respondents indicated that they had not had a transition plan and nearly half of the respondents indicated they did not have the information they felt necessary for the person they cared for to transfer successfully into adult services. This negative finding was replicated within the focus groups where the feeling was expressed that the transition process was particularly challenging and stressful. Hudson (2006) points to the fact that transition planning has not been particularly successful despite attempts to make improvements by the UK government. Hudson suggests that inter agency divisions and an inability to work together are key factors in maintaining this shortfall. Lack of information in many areas, including child and adult transition, was highlighted by this study.

Furthermore, following transition there was a feeling that the services available for adults fell far short on those received by children. This finding is supported in the work of Tarleton and Ward (2005). These authors point out that parents and carers reported feeling scared by the transition process and felt that there were limited opportunities for their offspring with a reliance on day centres and college placements. Within the Tarleton and Ward study parents (and young people with a learning disability) wanted basic information such as what is transition, what services are available locally, what rights and entitlements exist, and whether there are specialist transition workers. Again the current study upholds these findings.

Within the current survey there was a feeling that young people were simply fitted into adult services rather than the services being tailored to meet the individual's needs. This feeling of a dearth of adult services was also noted in relation to health care where the relatively joined up services provided to children were replaced by a feeling of fragmentation and lack of information generally.

Conclusion and recommendations

Carers want greater choice, flexibility and support in terms of the type of educational establishment available. They believed their views are not currently being given sufficient consideration when school placements are being decided. Efforts should be made to improve this situation and for carers to better input into the educational process generally.

Again, the quality and quantity of information provided to carers regarding transition plans (early and adult) should be improved to ensure that parents and carers both understand, and can make a meaningful contribution to, the transition process. The Federation should explore how carers can be better and more fully supported during transition periods which often produce additional stress and anxiety to both carers and the people they care for.

Work, Accommodation & Leisure

Work

Within the study only a third of people with learning disabilities, over the age of eighteen, reported any work related activity. However, this figure is somewhat misleading as a further analysis shows that two thirds of this group were not receiving payment for the work undertaken. Equally worrying, of those who worked the large percentage only did so on one or two days a week. This illustrated that despite policy initiatives to increase the level of employment of people with a learning disability (Department of Health, 2001) the overwhelming majority are not employed. Similar findings were identified in a study by Emerson et al (2005) who, in a large scale study of people with learning disability and their carers in England, identified that only 17% of people with a learning disability of working age had employment. Two thirds of people in the Emerson study reported they were unemployed but would welcome the opportunity to work. This was the feeling generated in the current findings.

The study also found that the majority of people with learning difficulties worked in either in shops or cafés. Only 4% reported working in outdoor settings. What is not clear from the finding is the actual amounts of remuneration (if any) the individuals receive. A number of comments in the focus groups were particularly telling with one carer suggesting that having their relative in employment was stressful in case the individual lost their job and became distressed by this. A particularly troubling example was given by one carer who actually paid an organisation (the reverse of a normal employment situation) to allow their learning disabled relative to continue in employment.

Accommodation

In discussing the findings in relation to models of accommodation it is important to note that the views expressed are those of the parents and not those of the individuals with a learning disability. Yet, equally it is entirely relevant to identify accommodation models that parents and carers support or feel confidence about for the accommodation or future accommodation for their loved ones. Of the choices provided more than half of respondents supported shared home with own tenancy, living with parents or a relative, a small home attached to the family home or a model based on the principle of core and cluster. However it has to be recognised that again some parents and carers were not entirely clear of the options available and more information on potential accommodation, applicable to individual needs, is needed.

Leisure

The study found that despite the limited leisure activities being undertaken by people with learning disabilities parents and carers were able to provide a long list of activities they would like them to participate in. People with learning disabilities were therefore not hindered by lack of carer aspiration but by inadequate service provision. Leisure activities play a major role in developing friendships and a feeling of psychological and sociological well being (as well as potentially improving fitness). It is therefore disappointing that within the current study nearly one third of parents and carers report that their relatives did not participate in *any* leisure activity. Quality

of life indicators suggest that leisure is a major factor in the continuance of good mental health and the high levels of challenging behaviour, depression and other mental health within the learning disabled population may be a factor in the lack of leisure activities (and work opportunities) being undertaken by this client group.

However, despite these findings in the focus group interviews carers were well able to provide positive examples about how leisure can make a significant difference to a person with learning disabled in terms of their general wellbeing; there were suggestions of developing independence, increased confidence and increased socialisation. Carers also noted the over reliance on key motivated individuals to maintain leisure activities and that the funding and profile of leisure activities was sadly seen as a low priority by service providers.

Conclusion and recommendations

Without doubt, people with learning disabilities are still not having their full potential acknowledged in the work environment. The Federation should lobby for closer collaborative working between Carers and those responsible for educational provision, and organisations such as Career Wales and local employees in an attempt to address this important issue.

Further research should be undertaken to extrapolate and examine data about the large group of people with learning disabilities who do not partake of any leisure activities; this should specifically measure the quality of life of those concerned and address potentially harmful psychological and physiological related issues.

Carers expressed an accommodation preference for a small home attached to parents/carers main home. Cost analysis should be undertaken to assess the financial implications of adapting or adding to the family home against alternative form of accommodation currently on offer.

Current Issues of Importance

Carers identified a number of issues currently causing them concern; such as access, quality and quantity of respite care, suitable educational provision and access to health and social care information. They also wanted to know that there would be a stable, secure and caring support available to the person with learning disabilities when they were no-longer able to care themselves. Clearly, the risk of parent and carer stress and burnout is exacerbated when carers have unaddressed worries and concerns,

Forward planning and anxiety regarding the future for their off spring are clearly key issues to parents and carers within this survey. There is also the finding that despite the structures that are currently in place, parents and carers still indicate that they feel they need more support accessing both appropriate services and support. There is literature (Mencap, 2002) which suggests that local authorities are failing to plan for the needs of people with learning disabilities being cared for by older parents (specifically in relation to accommodation). Bowley and McGlaughlin (2006) also suggest that in a survey of 56 parents, who were over 70 years of age, many were either not ready to discuss the future needs of their off spring or were unwilling to

make plans. One of the reasons given for this was a lack of confidence of existing service provision. These authors stress the importance of proactive planning to avoid the need for a crisis intervention. This is of particular relevance to the respondents in the current study as it has been identified that twenty percent of carers are over 65 years of age.

Within the focus group interviews the issue of continuity and the assured continuation of services was raised, as were the anxieties regarding what happens to their offspring when the parent and carer has passed on, or can no longer undertake the caring role e.g. 'who will care when we can't?' The need to develop more appropriate services was indicated along with the very real concern expressed that some people with a learning disability could find themselves in inappropriate settings, such as nursing homes. This is clearly a valid fear of carers as other authors such as Kerr et al. (2006) have also raised this concern. Parents and carers wanted to see their loved ones have longer term security of tenure, therefore the introduction of a tenancy or similar arrangement was seen as a step forward. However, the difficulty of accessing residential accommodation (as well as respite care) was evident in this research. These areas were also highlighted as the key issue in the electric voting.

Recommendations

What was evident from the study findings was that carers wanted to know there would be a stable and secure care package available when they were no-longer able to care themselves. The *Valuing People* White Paper (Department of Health, 2001) requires that services secure a plan for all service-users with learning disabilities living with older carers and promises them and their families more choice and control over how and where they live. Cardiff and the Vale has an aging population of parents and carers who are clearly anxious regarding their ability to care in the long term; this impacts on the type, quality and amount of care available to their offspring (or person they care for) in the short, medium and longer term.

Other issues of concern were carers' clear need for planning, access to and information dissemination in relation to the availability and the scope of health and social care services. In addition, reoccurring issues of respite and educational provision were highlighted along with the need for a more independent living agenda for the person being cared for. The Parent Federation may wish to consider producing literature to support older parents and carers and/or the development of a help/support line to provide both information and assistance to address carers concerns. Meanwhile, further research in the emerging area of carers' anxiety in relation to their inability to care in the long term must be conducted as a matter of urgency.

Clearly, the risk of parent and carer stress and burnout is exacerbated when carers have unaddressed worries and concerns, the Federation should therefore engage with as many members and agencies as possible to explore how carers current concerns can be addressed.

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Appendix 1

Reference number: [to be completed by the research team]

This first section is about You

Your Name:.....

Your Address:.....

.....

.....

Telephone contact:.....

Email contact:.....

Q1. Age (please tick as appropriate)

16 to 24 25 to 34 35 to 44 45 to 54 55 to 64 over 64

Q2. Gender

Male Female

Q3. Do *you* have

Physical Disability

Sensory Disability

Mental Ill Health

Other disability Please specify.....

Q4. Are you in good health? YES NO

Q5. Your first language

English Welsh Other Language Please

specify.....

Q6. Your ethnic origin

White

- British
- Welsh
- English
- Scottish
- Irish

Black

- African
- Caribbean
- Black British
- 'Mixed' race or dual heritage

Asian

- Bangladeshi
- Indian
- Pakistani
- 'Mixed' race or dual heritage
- Asian British /Welsh
- 'Mixed race' or dual heritage

East Asian

- Chinese
- Vietnamese
- 'Mixed' race or dual heritage

Instruction box

Please answer the following questions about the person you care for.
If you care for more than one person with a learning disability please choose one person you care for and answer the questions with this person in mind.

Q7. Do you consider your Caring Role to be **FULL TIME** or **PART-TIME**

Q8. Please describe the nature of your caring relationship, (e.g. are you a Mother caring for a Son or a Son caring for a Sister etc.)
.....

Q9. Do you receive any help in caring for your child or relative from another person? (e.g. from your husband/wife/partner/sibling/other relative/friend /social services/agency staff/professional carers). YES NO

Instruction box

If you answered YES to Q9. please answers questions Q10, Q11 and Q12 in this section. Otherwise please go on to the next section.

Q10. Do you or the person you care for pay for this help?

YES NO UNSURE

Q11. Are you satisfied with the quality of this help?

YES NO UNSURE

Q12. If you receive help in caring for your child or relative, either from a Relative, friend or from a professional, please give us some information about the type of assistance you receive

EXAMPLE:

Who helps you care for your child or relative: e.g. Husband/Friend/Social Services /outside agency etc.	Total number of hours per week they help you in your caring role	How reliable are they? <i>1 = very reliable</i> <i>2 = reliable</i> <i>3 = generally reliable</i> <i>4 = not very reliable</i> <i>5 = unreliable</i>
Husband	10 hours	2

Who helps you care for your child or relative: e.g. Husband/Friend/Social Services/Private sector provision etc.	Total number of hours per week they help you in your caring role	How reliable are they? <i>1 = very reliable</i> <i>2 = generally reliable</i> <i>3 = reliable</i> <i>4 = not very reliable</i> <i>5 = unreliable</i>

Accessing Healthcare

Please tell us about your experience of obtaining healthcare for the person you care for.

Q13. How easy is it to access the following healthcare professionals and specialist support services?

	Not Applicable	Impossible	Difficult	Easy	Very Easy
Family Doctor (GP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital Outpatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital Inpatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech & Language Therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational Therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling Therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Visitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Social Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Health Professional (Please specify)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

Q14. How easy is it to obtain healthcare equipment for the person you care for?

Not Applicable	Impossible	Difficult	Easy	Very Easy
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q15. How easy is it to change or upgrade Healthcare Equipment for the person you care for?

Not Applicable	Impossible	Difficult	Easy	Very Easy
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Educational Provision

Instruction box
 Please complete this section if the person you care for is currently IN EDUCATION or HAS LEFT school/college WITHIN THE LAST FIVE YEARS. Otherwise please go on to the next section on PAGE 7

Q16. Is the person you care for currently in

Full time education **Or** Part-Time education
Or in full/part-time education in the last five years

Q17. Is the person you care for currently attending

School F.E. college *or* left school/college within the last five years

Q18. What type of school or college does the person you care for currently attend/or attended in the last 5 years?

Mainstream school Special school Special unit within mainstream school

Other please specify.....

We would like to know *your opinion* of the different types of Educational Options available to people with Learning Disabilities. Please tick as appropriate.

	Strongly Dislike	Dislike	Neither Like or Dislike	Like	Like
Strongly					
Q19. Mainstream School	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20. Special Schools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q21. Special Unit within mainstream School	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q22. Has the person you care for been offered a *Choice* about the type of school they attended?

YES NO UNSURE

Q23. Has the person you care for been offered a Statement of Special Educational Needs?

YES NO UNSURE

Instruction box

Please answer question **Q24** (A,B & C) if the person you care for is currently in education and has a Statement of Special Educational Needs. Otherwise please move on to the next section.

Q24.

A. Is this statement UPDATED every year?

YES NO UNSURE

B. Are you INVOLVED in the updating process?

YES NO

C. Are you SUPPORTED in the updating process?

YES NO

Planning and Provision of Early Transitions

By *early* transition we mean the move from childhood into the teenage years which usually takes place around the time a child leaves primary school and enters secondary education.

Instruction box

Please only complete this section if the person you care for is aged between 10 & 14 years. If not please move to PAGE 8

Q25. Has your child/or person you care for received an *Early* TRANSITION PLAN?

YES NO

If you answered **YES** to this question please answer the following questions in this section otherwise please move to the next section.

Q26. Have you have been offered **sufficient** information to help you and the person you care for make choices about early transition plans?

YES NO UNSURE

Q27. Please tell us about any help, advice or information you have received while making decisions about Early Transition Planning and Provision

(Please write clearly in this box)

Q28. Is there any **ADDITIONAL** Support or Information that you might have wanted when making decisions about early transition plans?

(Please write clearly in this box)

Planning and Provision of Transition to Adulthood

We all “*move-on*” throughout life whether from college to work or leaving the family home to live on our own. For someone with a Learning Disability additional preparation and planning may be necessary for the process to be success.

Instruction box
Please complete this section if the person you care for is aged between 14 & 25 years. If not please move to Question Q36.

Q29. Have you been offered support in planning for Adult Transitions?

YES NO

Instruction box
If you answered YES to question Q29. please answer the following questions in this section. If you answered NO please move on to the next section.

Q30. Have you been actively involved in planning for Adult Transition?

YES NO

Q31. Do you feel as a carer that you have been given enough information about the available Adult Transition options?

YES NO UNSURE

Q32. Have the Options offered to you about Adult Transitions met your expectations?

YES NO

Q33. What information were you given about Adult Transitions?

(Please write clearly in this box)

Q34. Is there any additional information about Adult Transitions that you might have found useful in making these plans?

(Please write clearly in this box)

Q35. Who do you think should provide information about Adult Transitions?

(Please write clearly in this box)

Q36. At what age do you think information about Adult Transitions should first be provided? (please tick one of the boxes below)

Age:

12 to 14 15 to 16 17 to 18 19 to 20 Over 21

Activities – *Employment*

In this section we want you to tell us about the type of activity the person you care for takes part in on a regular basis.

Q37. Does the person you care for take part in any work-related activities?

YES NO

Instruction box

If you answered yes to question **Q37**. please answer the remaining question in this section. If you answered no please move on to the next section.

Q38. Please tell us about the type of work-related activity the person you care for takes part in.

EXAMPLE

LOCATION OF WORK ACTIVITY	WHAT DO THEY DO?	TIME SPENT ON WORK RELATED ACTIVITY	Paid or unpaid work
Local hardware store helping customers	Helping Customers	2 mornings a week	unpaid
Hairdressers	Stylists assistant	All day Saturday	paid

LOCATION OF WORK ACTIVITY	WHAT DO THEY DO?	TIME SPENT ON WORK RELATED ACTIVITY	Paid or unpaid work

--	--	--	--

Activities – Leisure & Recreation

Q39. Does the person you care for take part in any Leisure & Recreational activities? YES NO

Instruction box
 If you answered YES to question Q39. please answer the remaining questions in this Section. If you answered NO then please move on to question Q42.

Q40. Please tell us about the type of leisure & recreational activities the person you care for takes part in on a regular basis.

EXAMPLE

What type of leisure activity do they take part in?	Where does this activity take place	When do they take part in this activity?	Do you or the person you care for pay for these activities?
Dancing	Local dance school	1 evening a week for one hour	Yes Pay for
Day Centre activities	Day Centre	All Day Monday and Wednesday	No Free

What type of leisure activity do they take part in?	Where does this activity take place	When do they take part in this activity?	Do you or the person you care for pay for these activities?

Q41. Please tell us about any other kind of leisure & recreational activities the person you care for takes part in

.....

.....

.....

.....
Q42. What type of leisure & recreational activities would you like the person you care for to take part in?

.....
.....
.....
.....
.....

Accommodation

People with a Learning Disability need a variety of different levels of accommodation support in order to live full and rewarding lives.

Q43. Do you have a preference for one particular type of Accommodation Option?

YES please specify..... NO

Q44. Please give your view of the following accommodation models

A) Where a person has their own legal tenancy in a home shared with a small group of people.

Favourable Opinion No Opinion Unfavourable Opinion

B) Living with parents or relatives:

Favourable Opinion No Opinion Unfavourable Opinion

C) A small home attached to parents/relatives main home:

Favourable Opinion No Opinion Unfavourable Opinion

D) "Village Communities" where disabled people live together in a discrete setting:

Favourable Opinion No Opinion Unfavourable Opinion

E) Several people live in a community with regular support as agreed by local team of workers (Core & Cluster):

Favourable Opinion No Opinion Unfavourable Opinion

F) Warden assisted accommodation:

Favourable Opinion No Opinion Unfavourable Opinion

G) Adult fostering or supported lodgings, usually characterised by shared family living, including shared meals and recreation (Adult family placement).

Favourable Opinion No Opinion Unfavourable Opinion

H) Living alone, with own tenancy:

Favourable Opinion No Opinion Unfavourable Opinion

“Respite”

By respite we mean a service or reliable opportunity that gives you a break from caring or increases the independence of the person you care for. The service could be a residential home ‘sitting service’ or a regular activity or routine that the person you care for enjoys, that also gives you a break when you need it, or anything you consider as a break from your caring role.

Q45. Do you receive any Respite Support? YES NO

If you answered **YES** to this question please answer the following questions in this section. If you answered **NO** please move on to question **Q50**.

Q46. Please indicate your level of agreement with the following statement by ticking **one** of the boxes below

“The respite support I receive is flexible enough to suit my needs”

Strongly agree.....

Agree.....

Neither agree nor disagree.....

Disagree.....

Strongly disagree.....

Q47. What type of respite opportunities does the person you care for regularly take part in?

(Please write clearly in this box)

[Empty rectangular box]

Q48. How much respite time per month do you have?.....

Q49. Where is the respite support offered?

In a community setting

At home

Short breaks away

Other

(please stipulate other type of respite support).....

Q50. What type of respite support you like?

(Please write clearly in this box)

[Large empty rectangular box for handwritten response]

This section is about the person you care for who has a Learning Disability

Q51. Is the person you care for MALE or FEMALE

Q52. How old are they?

Q53. How would you describe their ethnic origin?

- | | |
|--|---|
| <p>White</p> <p><input type="checkbox"/> British</p> <p><input type="checkbox"/> Welsh</p> <p><input type="checkbox"/> English</p> <p><input type="checkbox"/> Scottish</p> <p><input type="checkbox"/> Irish</p> <p>Black</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> Black British</p> <p><input type="checkbox"/> 'Mixed' race or dual heritage</p> | <p>Asian</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Indian</p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> 'Mixed' race or dual heritage</p> <p><input type="checkbox"/> Asian British /Welsh</p> <p><input type="checkbox"/> 'Mixed race' or dual heritage</p> <p>East Asian</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Vietnamese</p> <p><input type="checkbox"/> 'Mixed' race or dual heritage</p> |
|--|---|

Q54. Is their First Language

English Welsh Other Language (please specify).....

Communicates non-verbally

Q55. Do you consider the person you care for to have

- A MILD or MODERATE Learning Disability?
- or
- A SEVERE or PROFOUND Learning Disability?
- Or
- NOT KNOWN

Q56. Does the person you care for have

- Difficulty with learning
- Difficulty with their sight
- Mental health difficulties
- Physical difficulties

Q57. Does the person you care for have a Key Worker, Social Worker, Care Manager or Community Nurse?

- YES NO If YES please specify.....
- *
- *

Q58. Has the person you care for had an assessment in the past year?

- YES NO

Information

Q59. Have you heard of, or been given information, about any of the following?

WOULD LIKE INFORMATION	YES	NO	GIVEN INFORMATION
A) Person Centred Planning <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B) Unified Assessment <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C) Benefit Entitlement <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D) Direct Payments <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E) Future Planning - Wills & Trusts <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F) Independent Living Fund <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G) Disabled Facility Grant <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H) Care Management <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I) Carers Assessment <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q60. What issues are currently IMPORTANT TO YOU as a Carer? Please use this space to tell us about anything that is important to you and/or the person you care for at the moment

(Please write clearly in this box)

Thank you very much for taking the time to complete this questionnaire.

Please post the questionnaire back to us in the envelope provided to ensure your views are heard by those developing services.

Appendix 2

Letter of Invitation

Dear Parent or Family Carer,

Re: Parent's Federation members survey
Seeking parents and family carers' views of current services received within the Cardiff and Vale local Authority region

Cardiff and the Vale Parents Federation have asked the Unit for Development in Disabilities (UDID) at the School of Care Sciences, University of Glamorgan, to undertake this independent research study. The 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 your local area.

We are writing to you to ask if you would like to take part in this study. Taking part in the study is entirely voluntary and the decisions you make about participation will not affect the services you or your relative receive in any way. We are keen to ensure that we speak on behalf of all parents/carers and hope that you feel able to contribute so that *your views* can inform the future planning of services. **All the information you give us will remain confidential and will not be attributable to you in any way.**

If you are willing to take part please complete the enclosed questionnaire and return it to us in the envelope provided by Friday 21st July. **There is no need to put a stamp on this.**

Appendix 3

Interview Schedule – Focus Group (Cardiff and Vale Parents Federation)

1. Services available

How do you / did you, find out about the services available to you?

PROMPT:

- Support groups you belong to
- School
- Services – such as the day care centre
- Professionals – such as key worker / social worker, medical professionals
- Internet
- How helpful is the PCF?

In the survey, many people suggested that they wanted more information.

What do you think is the most important information people need?

2. Access to GP's and dentists

- a. What is your **experience** of using these services?
- b. How **satisfied** are you with these services?
- c. How **helpful** is the GP in helping your relative to access services?
- d. What is your **experience** of using other services? (such as speech and language therapists, any others)

3. Emotional support

- a. Have you ever had the **opportunity** to receive emotional support (such as counselling) to support you as a carer?
- b. Is this **important** to you?
- c. Is there any **other** emotional support that would help you?

4. Respite care

- a. What do you **understand** respite care to be?
- b. What would you **want** from respite care?
- c. What do you think is **good** about respite care?
- d. What do you think is **bad** about respite care?

5. Educational provision (current or past provision)

- a. What **choice** did you have regarding the school that your relative attended?
- b. Do you have a **preference** for education in mainstream or special school environments?

6. Transition

- a. What do you think makes a **good** transition from children to adult services?
- b. What would / or would have **helped** you in the transition process?

7. Current issues

- a. What do you think are the most important issues for your relative's **future**?
- b. What are the **key issues** that would help you in your role as a **carer**?

8. Work and leisure

Few people with a learning disability have paid jobs and lots of people with a learning disability do not take part in leisure activities.

- a. What would you suggest could improve people's **opportunities** for employment?
- b. What type of jobs do you think would be **appropriate**?
- c. What would help make leisure activities more **accessible**?
- d. What **types** of leisure activities do you think could be provided?

Appendix 4

Focus Group One

No.	Question	Answers	Responses
1.	How important is it that Wales beat New Zealand in Saturday's rugby?	1. Very Important	1
		2. Important	1
		3. Moderately Important	1
		4. Of Little Importance	0
		5. Unimportant	3
2.	Who do you find is most useful when accessing information in your capacity as a carer?	1. Key Worker/ Professionals	-
		2. School	-
		3. Day Centre	-
		4. C & V Carers Federation	-
		5. Other support groups	5
		6. Internet	1
3.	Who best helps you meet the health needs of the person you care for?	1. General Practice	Not asked
		2. Key Worker	“”
		3. Social Worker	“”
		4. Care Manager	“”
		5. Community Nurse	“”
4.	Do you feel that YOU, as a carer, need emotional support?	1. Yes	Not asked
		2. No	“”
5.	Are you happy with the current respite provision that you receive?	1. Yes	3
		2. No	3
6.	Which of the following is the most important issue for you regarding respite?	1. Payment	-
		2. Flexibility	5
		3. Choice of venue	1
		4. Length of stay	-
7.	Which of the following do you feel is the most important in transition?	1. Choice	1
		2. Support from professionals	-
		3. Life skills & PD	1
		4. Information	4
8.	Which one is the most important to you?	1. Accessing service provision	Not asked
		2. Independence/ Quality of life	“”
		3. Information and Support	“”
		4. Respite care	“”
		5. Who will care when we can't?	“”
		6. Educational provision	“”

Focus Group Two

No.	Question	Answers	Responses
1.	How important is it that Wales beat New Zealand in Saturday's rugby?	1. Very Important	1
		2. Important	2
		3. Moderately Important	2
		4. Of Little Importance	2
		5. Unimportant	2
2.	Who do you find is most useful when accessing information in your capacity as a carer?	1. Key Worker/ Professionals	2
		2. School	-
		3. Day Centre	1
		4. C & V Carers Federation	1
		5. Other support groups	5
		6. Internet	-
3.	Who best helps you meet the health needs of the person you care for?	1. General Practice	8
		2. Key Worker	-
		3. Social Worker	-
		4. Care Manager	-
		5. Community Nurse	-
4.	Do you feel that YOU, as a carer, need emotional support?	1. Yes	7
		2. No	2
5.	Are you happy with the current respite provision that you receive?	1. Yes	2
		2. No	7
6.	Which of the following is the most important issue for you regarding respite?	1. Payment	-
		2. Flexibility	4
		3. Choice of venue	2
		4. Length of stay	3
7.	Which of the following do you feel is the most important in transition?	1. Choice	3
		2. Support from professionals	1
		3. Life skills & PD	3
		4. Information	-
8.	Which one is the most important to you?	1. Accessing service provision	3
		2. Independence/ Quality of life	2
		3. Information and Support	1
		4. Respite care	1
		5. Who will care when we can't?	1
		6. Educational provision	1

Appendix 5



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 []
- I understand I may withdraw from the study at any time without giving reasons []

Signature.....

Name (printed).....

Date.....

Signature of Researcher.....