Stepping Stones

Family-led Service in the South West:

Deaf children and their families

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The Report in Brief

Changes in policy and attitudes of central government in the last ten years have offered to parents of children with special needs a central role in decision-making in regard to their children in all aspects of service. Following a series of meetings beginning in 2005, a group of parents, professionals and researchers, set out a vision of creating an integrated family-focused and family-led set of services for deaf children and their families in the South West Region of England. The motivation for this effort drew on the experience of two "Early Excellence Centres" – one in East London and the other in the North West - and of the work of the Family Centre for Deaf Children (FCDC) in Bristol. As a precursor to the development, the Stepping Stones project set out to consult with representatives of the primary stakeholders in the region.

Funding for the project was obtained from the Medical Research Council Hearing and Communication Group in Manchester, within the developing context of the National Newborn Hearing Screening Programme and was supported by BANES PCT.

Background

The Every Child Matters Initiative (DfES, 2003) and the corresponding health initiatives (eg DoH 2007) have in turn led to a campaign in respect of children with special needs.

"Every Disabled Child Matters (www.edcm.org.uk) wants…

- Families with disabled children to have ordinary lives
- Disabled children to matter as much as all other children
- Disabled children and their families to be fully included in society
- All disabled children and their families to get the right services and support – no matter where they live
- Poverty amongst disabled children and their families to be cut by 50% by 2010 and eliminated by 2020
- An education system that meets the needs of each child and enables them to reach their full potential
- Disabled children and their families to shape the way that services are planned, commissioned and delivered

Not surprisingly there has been a convergence and a huge impetus to integrated service provision. A formal expression of this is in the creation of Childrens' Trusts (www.everychildmatters.gov.uk/aims/childrenstrusts) which draw together all services in order to provide the seamless approach which is thought to be needed. As this project has been undertaken the Government initiative on "Aiming High for Disabled Children" (http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC/) has come into force and this promises a great deal to parents . These developments are in their early stages and as we can see in the consultation carried out, has not reached the perceptions of parents of deaf children in the south west region. Our discussion with parents has the potential to inform the regional development and ensure more appropriate responses to the needs expressed.

What we did

We examined the current policy and research literature, we searched online for resources for deaf children in the South West, we talked to health and education staff involved in this work and we interviewed parents of deaf children. We obtained a considered view from the experiences of the Bristol Family Centre for Deaf |Children. We integrated these data sources and produced the report.

Our consultation with the professionals

The Newborn Hearing Screening Programme (http://hearing.screening.nhs.uk) has been introduced but the opportunities for families to shape the new services have been limited. The professionals have mainly relied on Children's Hearing Services Working Groups (explained for example at http://www.scotland.gov.uk/Publications/2009/01/23140147/11 or at http://hearing.screening.nhs.uk/cms.php?folder=1955) as a means of consulting parents about their services. Objective family-led assessments or evaluations of the services have so far been limited or absent.

Family groups as described, were mainly run by the professionals, and their uptake was generally variable. Professionals noted the limitations on fathers' involvement.

Among those who spoke to our interviewers, there was general support for the concept of a regional centre, but professionals raised a number of concerns that would need to be addressed. These include: the training and professionalism of parents who work with families, clarity about the respective roles of local and regional services and communications across a wide area.

An impression is left that professionals can only be expected to provide services within their own professional competence and remit. They are not placed to address the wider social and cultural needs of families.

On-line information about services in the South West

Despite the general policy of open access and provision of information on local services any parent would have found it difficult to discover such things as the school options for their own child, a named person to provide information and even the extent of service support to a child in mainstream school. Websites of education authorities and health trusts were poorly organised from this perspective. The information presented appeared in such a diverse form with different conventions, that it was not possible to determine which activities matched which in other Local Authorities and Health Trusts.

The Early Support programme (http://www.earlysupport.org.uk) provides online information designed to enable parents to take control of their child's progress, and this was identified by educators in our study as an important national resource.

Family Responses

A common assumption that there exist 'families of deaf children' as a group was quickly dispelled by the range of experiences and circumstances which we encountered. Parents brought together by services provision for their deaf children, are unlikely to share any life interests or common ground other than that their children have a hearing loss. It seems unlikely that a 19 year-old unmarried mother would share a great deal with a solicitor-teacher couple who just happen to have a deaf child of the same age. Yet it is a common concept expressed by service providers that 'parents of deaf children need x and should do y'. We found that some parents were overawed by the professional interventions while others wanted a more direct involvement. Some parents expected services to arrive while others wanted to challenge the service providers.

At the same time, children differ enormously. Some have minor losses which may be susceptible to surgical intervention, some may use sign language and see Deaf culture as the goal. Managing this diversity was immediately a challenge for a regional family centre although clearly working on a larger regional scale might offer more opportunity for the matching of families.

The notion that parents ought to be available at all times to support their children was also challenged by the reality of family life – which simply did not allow the parents time to attend hospital, meetings, learning sessions and be able to take the lead in working with other parents. Many would feel distinctly uncomfortable in expressing their views in public groups and would

not necessarily have management skills to take part in a family-led initiative. The idea of a family created and family run centre may need to be superseded by the concept of family-led and family guided.

Existing consultation methods with parents (eg Children's Hearing Services Working Groups (CHSWGs)) were seen as "talking shops" ie lacking power for change, by those parents who actually knew what they were (the minority). Typically, parents believed they were offered services which already existed and not given the opportunity and time to express their own needs as a family. In regard to contact with the various professional staff they met, families reported:

- Bias in professionals ie in respect of the other roles (accountability to education authority for example) held by the professional - there was a need for an independent voice in support.
- The actual value to the family varied enormously from one professional to the other and this was compounded by the fleeting contacts (they come and go over the child's lifetime)
- Social services departments generally were not seen as making any useful contribution

The Family Centre (Deaf Children)

We received a description and analysis of the work of the Family Centre. This centre in Yate, Bristol, is a family led organisation for Deaf Children and their families, that has been running successfully for 15 years. The FCDC is reported to work well especially for those within reach of Bristol. Parent participation increases and decreases over time as the child's developmental needs change. Having recently surveyed parent involvement, the Family Centre can identify priorities:.

- Support at the time of confirmation
- Maintenance of support after the time of school entry
- More and better social involvement – especially for school kids and teenagers
- Counselling / boosting self-confidence
- Access to sign language
- More support to and involvement of fathers.

Conclusions

Families clearly expressed the need for a type of provision that is not in evidence at this time in the South West region.. Independent support, matching to other families with similar experiences, opportunity to shape and select service provision, respect for the parent experience and aspirations – in effect the empowerment of the family voice - was considered to be unavailable at this time. Professional perspective is that opportunities for consultation exist and that personal contact with parents serves to give the targeted information for that child.

This is a preliminary study and is not meant to be exhaustive but rather consultative only on the appropriateness of the development of a family-led centre. A cross section of parents were reached and a small sample of health and education professionals. Their responses allow us to move forward.

Creating a regional centre?

A regional centre or focus for family led services could address many of the issues raised in the consultation process. Not least, it would provide a larger group of families, increasing the chances of families meeting others with whom they could interact. Considering the plan for a Regional Family-led Centre

Advantages might be:

- All services would be under one roof
- There would be consideration of all aspects of development: social emotional physical intellectual

- It would be expected to build on the knowledge and wisdom of parents of older deaf children, and on the experiences of the deaf young people themselves.
- There would be meaningful participation of Deaf adults
- It would host a bank of research knowledge
- There could be a much wider catchment area for families with more likely similarities in experiences
- There might be greater choice of professional support

Disadvantages might be:

- Location of a centre in one place would inevitably make it difficult to reach for some families
- There might be some fears that there would be corresponding loss of local resources

The next steps

We recommend that we move towards a more thorough stage of planning for a regional provision (physical centre or distributed facility) as follows:

1. Conference for professionals in the region to consider the report and to work towards collaborative applications for external funding for regional initiatives

2. Regional conference for parents to discuss the report and its possibilities

3. Creation of a regional information portal online

4. Regional pilots on specific issues with underlying parent-driven/ parent-led approach:
   young mothers workshop
   early parental experiences – sharing of strategies for daily life
   technical seminar series – use of the Internet, videophones, text messaging, interpreter services

5. Family database – closed membership of families allowing them to contact each other

6. Ongoing family conference to discuss progress in each of the above areas

7. Development and validation of appropriate outcome measures for use in initiatives

This preliminary work underlines the importance of parental views and indicates the significance of the whole family perspective with the appropriate involvement of parents and carers.

Chapter 1: Family-led Services

1.0 Background

Concern for families and recognition of their role in developing their own children are not particularly new themes in service provision. Yet even today, we continue to assert the value of consultation with parents without specifying a means to implement what they say. However, two major programmes have come into being in recent times which may produce change: the Every Child Matters initiative (DfES, 2003) and the Early Support Programme (DH, 2003). These in turn are built around the National Service Framework for Children, Young People and Maternity Services (DH, 2004).

There is also pressure to improve professional intervention: Children's Trusts were introduced by the Department of Health in October 2002, in England; the idea being to offer an integrated service for children. Children's Trusts are led by the local authority, being underpinned by the Children Act 2004 duty to cooperate. They aim to create a child-focussed service to meet children's needs rather than parents having to negotiate fragmented services, one after the other. We will explore these issues further below while at the same time, considering the situation of families with Deaf children.

1.1 Issues for Deaf children

Not surprisingly, the emphasis in the policy framework is on accessible care and the achievement of normality even though there is occasional mention of sign language.

> …professionals should … consider the needs of children who use non-verbal communication such as sign language. (paragraph 5.10, Department of Health, 2004)

The central guidance principle of the approach is Core Standard 8:

> Children and young people who are disabled or who have complex health needs receive co-coordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives. Page 7, Department of Health 2004

This derives from the Framework of Assessment of Needs (Department of Health, 2000) which considers a child to be "in need" if he/she is disabled. This disabled definition

applies also to Deaf parents who may need to be communicated with in British Sign Language (paragraph 1.45, Department of Health, 2000). The framework is couched in terms of support and action in favour of families, but there is a sense that normality is an expected aspiration.

> When assessing a child's needs and circumstances, care has to be taken to ensure that issues which fundamentally shape children's identity and wellbeing, their progress and outcomes are fully understood and incorporated into the framework for assessment. ….
> In assessing the needs of children, practitioners have to take account of diversity in children, understand its origins and pay careful attention to its impact on a child's development and the interaction with parental responses and wider family and environmental factors.
> To achieve sensitive and inclusive practice, staff should **avoid**:
> * using one set of cultural assumptions and stereotypes to understand the child and family's circumstances;
> (paragraphs 2.27-2.29, Department of Health 2000)

Plausible though this seems, it sets diversity not as a norm but rather as something which 'impacts on a child's development'. We need to make the underlying model much more explicit if we are truly to engage with families. The diversity which is presented above tends to be related to race/ethnicity and not to Deaf people. We find this also in Core Standard 8

> This standard locates the experience of disabled children and young people, and their families, within the wider community. It promotes their inclusion and their ability to live as ordinary a life as possible through effective partnerships with them, joint working between agencies, and a commitment to extending and improving services to meet their needs collectively and individually.
> (paragraph 2.6, Department of Health 2004)

Much emphasis is placed on inter-professional agency working. ToDs are increasingly working with Early Support which includes assessments of communication skills – including non-verbal – and these can be made by the family if they wish. Speech Therapy is mentioned in regard to assessing communication needs and even in facilitating communication. There is no profession of 'Deaf expert' and even though there are Deaf communication support workers in pre-school education services, none appear to have penetrated the Health Services (perhaps a few professionals with hearing loss in hearing therapy). There are a small number of Deaf workers in Social Services Departments but there appears to be no specific acknowledgement of their specialist skills.

The reduction of the median age of discovery of hearing loss in children from 20 months to 3 months of age (because of universal neonatal screening) implies significant

expansion of services to parents of infants. The guidance still contextualises the development in a hearing-centric way.

> Deafness in young children interrupts the developmental process for acquiring language normally observed in hearing infants. (paragraph 9, DfES 2003)

and

> Earlier identification of deafness, when combined with effective service provision in the pre-school years, will dramatically improve the chances of successful inclusion of Deaf children into mainstream schools and into society. It therefore has the potential to significantly reduce the long term costs to society of providing support services. (paragraph 11, DfES, 2003)

While there is indication that for example, sign language (a feature frequently requested by parents and Deaf people) is an option and that development of positive Deaf identity is a goal, the DfES guidance promotes Teachers of the Deaf (who are all usually hearing) as the Key Workers in the Early Support Framework (Key Worker here has a specific meaning as the contact and advisory point for parents in regard to all provision and development questions for their children). The theme appears to be that language equates to speech and normality; while sign language is a parental add-on. In effect, the model does not poll family views but rather offers to bridge the gap between families' current status as different and the supposed aspiration of the child to be hearing-normal.

It seems likely given the thrust of family services development, that Deaf people's expertise will not be used nor evaluated. Yet this has been the basis of the development of pre-school services in Bristol for at least 15 years (Sutherland & Kyle, 1993). An understanding of the language used for hundreds of years by the community is probably of importance in service delivery,

1.2 Recent developments in disability and families

Changes in policy and attitudes of central government (in the last 6 years) have offered to parents a central role in decision-making in regard to their children. In areas of special education and where the child has special needs, this parental role becomes even more significant.

The Department for Children, Schools and Families proclaims that families are of prime concern.

> Parents, carers and families are the most important influence on outcomes for children and young people. The Every Child Matters: Change for Children programme aims to ensure that support for parents becomes routine, particularly at key points in a child or young person's life www.everychildmatters.gov.uk/parents/ .

The expectation is that families should not only be central to decisions about their own child but should also be empowered to contribute to the shaping of whole services. The Children's NSF Standard 8, (Oct 2004) set a vision: to see children and young people and their families actively involved in all decisions involving them and in shaping local services. This message is continued in *Every parent matters* (2007), which says that engaging parents effectively means giving them the means to influence the shape of services.

Aiming High for Disabled Children (2007) has come into being during the lifetime of the project and in theory offers a great deal to parents (although not so obviously in a family-led format) (www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC). The programme highlighted evidence that services which involve users in their design and implementation are more likely to succeed with those they are trying to help. It presented an impressive **core offer** to disabled children, young people and their families, building on NSF standard 8. There are five parts to it:

1. Information
Disabled children, young people and their families can expect user-focused information that covers all services and providers.
2. Transparency
Disabled children, young people and their families can expect transparency about the principles concerning allocation of funds. The government has set out delivery milestones for each of the core standards.
3. Assessments
Disabled children, young people and their families can expect assessments that are based on the necessary consent to share information and an understanding of the purpose and possible outcomes of the assessment – and focused on promoting the welfare of the child in the family
4. Participation
Disabled children, young people and their families can expect participation through:

- Choice over the support provided and full involvement in assessment and design of their packages of care
- The opportunity to contribute to decisions about local service development
- Arrangements to facilitate such contributions
- Tailor-made opportunities for disabled children and young people to participate in service planning and development
- Involvement in drawing up and monitoring the disability equality scheme

5. Feedback
Disabled children, young people and their families can expect feedback to be routinely and systematically sought from all children and families

An initial task for AHDC has been to initiate a system change which is to be driven by two main factors:

A. Performance management using a standard national measure or indicator (NI54). This new indicator assesses parents' general experience of services for disabled children (aged 0–19 years) and service delivery across the health, social care and education service sectors according to the five elements of the AHDC core offer. An initial report from 30 local authorities provided a baseline and an overall score (DCSF, BIS May 2009).

It gave a parental satisfaction figure for England of 59 out of 100. This low figure is mainly due to very low scores in the area of "feedback".

B. Strong parental engagement, seen as critical to make the core offer work locally. This work stream is designed to develop the active involvement of parents in service planning and decision-making processes at a local level to ensure that parents are active agents in shaping services. A total of £5m has been allocated to support parent participation through a programme of grants and support over 2008–9 to 2010–11. Some areas used the grant to involve parents from different backgrounds, covering a wide range of experiences, including type of disability and groups who find it harder to get involved. Others developed websites and e-forums so that parents who found it difficult to attend meetings could have the opportunity to feed in their views and experiences.

Together for Disabled Children

Together for Disabled Children (TDC) is the national delivery agent supporting local authorities and PCTs. Within their programme, a parent advisor provides support for parent forums and facilitates activities to engage parents in the planning and commissioning of services. (www.togetherfdc.org)

"Effective practice in commissioning in children's services" (DCSF March 2007) provides a summary of the DCSF effective practice case studies on commissioning. Better commissioning and market management in children's services is at the heart of DCSF plans to improve the delivery of services to children, young people and their families. It concludes:

> "Encouragingly the case studies confirm that children young people and their families are becoming increasingly involved in the design delivery and evaluation of the services. There was however little evidence in these case studies of what users felt about this involvement or gained from it."

The Parental Involvement in Commissioning initiative (http://www.dcsf.gov.uk/everychildmatters/strategy/parents/pip/PIPrkparentalinvolvementcommissioning/PIPparentalinvolvementcommissioning) sets out clearly the matrix of involvement (Figure 1.1)

Figure 1.1 Parental Participation

The highest level of involvement implies delegating the budgetary control to parent groups, who would run the services. It seems uncertain at this time, when or how this can be achieved.

1.3 The challenge for families in general

Typically, parents are not familiar with the problems they are to face as the child grows and are usually unprepared for the impact that the situation will have on their existing family and lifestyle. While promoting family decision-making, service professionals have also to act as an information resource and support to the parents – for some, they may be the only source of information. The extent to which that support is guidance rather than counselling and the extent to which the Local Authority existing provision, finances and philosophy act to narrow the choices for families and thereby the amount of information supplied, is not well discussed in the paperwork. Realistically, support begins from the existing network of provision in each Local Authority or Health Trust.

Parents are expected to exercise informed choice and this is likely to provoke a series of reactions. On the one hand there may be dismay, disappointment, recrimination at the

discovery of hearing loss in the child, while on the other hand there will be commitment to change and active search for solutions as the child is accepted into the family.

We can expect a mobilisation of resources to do the best for the child. These resources will vary from family to family depending on their personal circumstances including socio-economic status, abilities in managing the information flow, professional contact, age and structure of the family itself. The fact that different families have a child with similar problems, in itself, may not be a sufficient reason for parents to come together, to share resources or even to become a community. The nature of the family relationships (their extended families, languages and cultures), the child's characteristics mean that the contact with professionals and the capacity to deal with the accessible information, creates an extraordinarily complex pattern.

1.4 Review of existing work

As a starting point for our consultation with parents and professionals, an examination of published literature on family–led service was carried out. The review focused in turn, on

- Family-led services in general
- Family services where there is a Deaf or hard of hearing child

The key question when considering the published information is whether there is evidence that family-led services help or make a difference to the lives of the families and to the development of the child?

We had imagined that there would be an extensive literature on the central role of families and on the way in which services had been configured to take this into account. However, this appeared not to be the case and although we found much to confirm the importance of families, there were very few circumstances when a true 'family-led' initiative was in place.

1.4.1 Background to the review

By family-led, we mean to imply that the needs and aspirations of the families are defined by themselves and not by existing provisions or patterns of services. We further imply that the decision-making following access to a range of information is in the hands of the individual families and this decision-making includes the extent of contact with

professional support and in particular, the opportunities to contact and to interact with other families. We acknowledge that this is not a formula for solving specific problems nor that each family is expected to develop in independence and isolation from traditional approaches. However, there are many different types of family groupings.

> "If we define a child's family in narrow terms based on stereotypes or on our own limited experiences, on the "caseload" demographics of an agency, or even from research, then we have already jeopardised the possible achievements of family-centred services…Because families are the ones who see their child on a continuous basis, and in a variety of settings, through developmental stages, they really are the experts." (Shelton and Stepanek 1994)

The family may experience a range of social and health conditions in addition to having at least one member who is hard of hearing or is Deaf. Our starting point for the consultation exercise, described below, is the principle that the family is the only constant in the development of the child and that is where we should begin our planning.

Our definition of 'Family-led' where the control and decision-making on the support and interventions for any member of that family are determined by the family itself and not just 'provided' appears in the literature relatively rarely. In most models, parents are meant to be recipients of services designed by experts to support the family in managing a disability. Although there is usually a process of consultation, the reality is that parents are expected to acknowledge and accept the problem/difference (on behalf of their child) and to embrace the service concept before services are to be provided.

Many publications use the term family-led when in fact what is meant is the scenario where professionals are working with family groups in a leadership or guidance role. The families while nominally the decision-makers may not have access to independent advice (i.e. separate from local authorities or suppliers) and may find the extent of the professional training of their advisers both a help and an obstacle.

Accounts in the literature rarely report assessment of the effectiveness of services provided whether professional–led or parent-led (other than in a structural or management sense) although there are many descriptions of the service planning and implementation. It is clear that the examples we discovered and described below do not fit the definition of family-led development. What most of the organisations describe is work ***with*** families and not outcomes determined ***by*** families.

The most common development is of family-*centred* provision. Rather than evaluate services as such, much of the written material on this topic concerns good practice or policy on how to create and manage a family provision. For example, there are guidelines in setting up a family support group (www.hearing.screening.nhs.uk) .

This guidance identifies important issues going some way to placing parents at the heart of it but offers no real structure for family participation. It offers no means of evaluation of success nor any indication that the 'parent-led' component is realised and effective. These approaches are also promoted within a framework of training for professional staff (see www.hearing.screening.nhs.uk under training and consultancy). There is clearly a professional understanding of the complexity of the issues and the factors which might be significant to success; however, there are few reports of implementation or of evaluation.

One underlying theme apparent in these descriptions is that family groups are for families with *small* children. The activities described for the children are aimed at young children such as those children who attend Sure Start[1]. This appears to be somewhat odd in that in the case of families with Deaf children we can expect at least the same level of need and provision when the child is an adolescent as when he/she is in infancy.

1.4.2 Evidence of family-led services in general

In a randomised study of family-led education investigating psychological well-being and relationship outcomes, Pickett-Schenk et al (2006) studied 462 family members of adults with a mental illness in 3 south eastern Louisiana cities. The results showed that family-led interventions are effective in improving not only participants' psychological well-being but also their views of their relationships with ill relatives (Pickett-Schenk et al 2006).

The Child, Youth and Family's Care and Protection Practice framework (http://www.msd.govt.nz/publications) is claimed to be a key mechanism for strengthening practice with children and families in New Zealand. Designed as a tool for

[1] "Sure Start is the Government programme to deliver the best start in life for every child. We bring together early education, childcare, health and family support". http://www.surestart.gov.uk/

practitioners, the practice framework integrates three perspectives: child-centred, family-led & culturally responsive, and strengths & evidence-based.

Connolly (2007, from the Ministry of Social Development in Calgary) examined the ethical issues in child and family practice in respect of the mental health care of the children. The ethical issues included ways in which parents could contact the Clinical Ethics committee with any concerns regarding ethics. She considered that the general family-led model is characterised by extended family-driven decision-making and family solution-focussed processes. It is clear when she writes about level of participation in the Southern Alberta Child and Health Network that although the family is consulted, in actual fact, the major decisions are made by professionals. The practice continuum, as she describes it, is characterised by family-centred processes but with professional involvement at critical decision-making times.

However, in Sweden, discussion regarding health and the family relates to family-led counselling. Olander (2005) of the Blekinge Institute of Technology has produced a presentation that includes the following contrasting scenarios (missions) and which illustrates the different orientations of public versus family services:

Public health mission
Content as a part in the country's health promotion

- CHS and expert led
- Health information
- Top down
- Low participation
- Advice giving

Family health mission
Content from the individual family's needs

- Child- and family led
- Health counselling
- Bottom up
- High participation
- Advice conferring

(http://www.fhi.se/upload/BestPractice/FR5013E_Olander.ppt#2)

The CHS are child health nurses who have a well-established history of health promotion. This health counselling is aimed at families with young children. The meetings are family-led in that the families negotiate the content; however, even so, it would seem that the professionals have a primary role in the meeting.

The Community Development Initiative of Arizona (Arizona Department of Health Services/Office for Children with Special Health Care Needs/Systems of Care 2004) is for families and agencies to work hand in hand to develop and to enhance self-reliant, self-

sustaining communities. They use terms such as "Circles of Success" and "Communities of Strength" in their work. Parent leaders invite professionals to join them in their community development work. Importantly, parent leaders are reimbursed for the time spent in leadership activities.

Barker (1984) led a project that aimed to help the development of infant children living in some of the most disadvantaged areas of the UK and Ireland. In his model, parents became advisers to other parents and visited them at home (and were reimbursed).

> It is thought that by offering support to the parents and advising and cooperating with them in the rearing of their children, the effects on the children are likely to be more permanent than could be expected if the programme was concentrated on professional interaction with the children. (Barker 1984 *Child Development Programme* University of Bristol in collaboration with Bernard van Leer Foundation p.9)

The Parent Support Project set out to revolutionise parenting among the disadvantaged within the three cultures in which it operated – England, Wales and Ireland. In the measuring of the project effectiveness, five trained interviewers interviewed the parents. The parents themselves expressed great appreciation of these assessment interviews, explaining that nobody had ever before spent two hours enquiring about the mothers' views and achievements in child-rearing (Barker 1984).

An important UK initiative in the field of parent support was Home Start, a community-based programme in which women were recruited and trained to provide a home-visiting service for parents, particularly mothers, who have run into problems (Barker W & Anderson R. (1988) *The Child Development Programme: an evaluation of process and outcomes,* University of Bristol in collaboration with Bernard van Leer Foundation). The programme was ahead of its time and ran into difficulties with health professionals who did not feel that parent-parent interaction discussion was appropriate. Nevertheless, the response from the families themselves was overwhelmingly positive.

The University of South Florida has described a range of family based organisations involved in the care of children with serious emotional disorders. They describe the presence of a *strong family voice* when dealing with these disorders. (http://rtckids.fmhi.usf.edu/rtcconference/handouts/default.cfm?appid=19127)

Other types of family-based schemes include working for a supply of water in parts of Africa and business-led families working for better energy in Asian countries. This seems

to take us far from our notion of family-led services as such. The point is made in Japan that social welfare is unlike that of the Western World in that there is an emphasis on self-help, mutual and market welfare activities and enterprise welfare. This will involve the extended family.

In the UK, when Children's Trusts were introduced, 35 "Pathfinder" Trusts were funded. An evaluation of their first year has been reported (National evaluation of children's trusts. Phase 1 report. University of East Anglia in association with the National Children's bureau. 2005)

- Responses from parent panels suggest that children with multiple complex social care and health needs for example disabled children are substantially under supported across the case studies sites. Both parents and young people highlight the difficulties in finding information about the services available to them.
- Information sharing and common assessment processes are being piloted in some areas, but are not operational generally.
- The professionals interviewed were generally committed to develop service user participation, and report modest levels of service user engagement.
- There was substantial variation in the ways in which areas are involving parents and carers in Trust arrangements. Three case study areas had made formal provision for parents to sit on their statutory boards, but this involvement was not confirmed by the interviewees. Many areas are still devising their participation strategy.
- There is a lack of systematic approaches to participation, and a lack of clarity about the type and extent of the user participation required.
- The organisational structure of children's services is changing, but the cultural climate is changing more slowly.

Revised guidance in November 2008 raises the bar for Children's Trust partners to champion and take responsibility for achieving measurable improvements. It aims to help partners engage more effectively within the Children's Trust and to promote a step change in early intervention, in narrowing the gap.

Although some further examples are described in the literature, there are few analyses of the factors which produce positive results.

In Montreal McGill University set up a family support group to help the family to deal with cancer (http://www.muhc.ca/media/ensemble/v01n02/family/).

In New Zealand research examined parents of very small children and showed how they made contact with each other to their mutual benefit (http://www.minedu.govt.nz/web/downloadable/dl11310_v1/21-dec-05-summary-report---final-web-version.doc).

From these few studies and descriptions, we came to the conclusion that it is almost impossible to find evaluation of services where parents have been given a lead role in determining the extent and purpose of the intervention offered by the State.

The Barnardo's study of what works in services for families with a disabled child summarised their findings:

- They noted a lack of good evaluative evidence on what works in services for families with disabled children.
- The research into what mothers needed was good; however there is little research into the needs of fathers, siblings and of grandparents.
- Evidence of the needs of the disabled child is gained from mothers' views.
- It is not common to find detailed descriptions of services or evaluations of services.
- There is no one blueprint for an effective service.
- Evaluation of services for disabled children needs to ask two questions (i) What works? and (ii) For whom?
- Methodologies for accessing the views of disabled children are underdeveloped. (Beresford, B., Sloper, P., Baldwin, S., Newman, T. (1996) *What works in services for Families with a Disabled Child* Ilford: Barnardos)

The pattern is similar throughout our review of published documents with a great deal of description of the provision and very little evaluation.

1.4.3 Other initiatives

There are a range of other initiatives with no reference to evidence on success. In the UK CAMHS (Centre for Adolescent Mental Health, North Kensington) (http://www.rbkc.gov.uk/camhs/about/about_actions.asp) has facilities for the counselling of teenagers and young people, help for parents with their children and help for parents including teenage parents. This type of help is also mentioned by a variety of organisations in Scotland which also describe the place of Family Group Conference Services. (http://www.children1st.org.uk/about/services.html)

Family Group Conferences were first introduced in New Zealand but the concept is now used in many countries across the world, including Northern Ireland and the Republic of Ireland. Family Rights Group works with families involved with social services. They produce campaigns to challenge injustice, improve access and increase the voice of children and families. It can be seen from these examples that the work described is essentially work normally done by the social services.

Another initiative is the work on family interaction in the promotion of recovery of people with severe and enduring mental health needs (North Glamorgan NHS Trust) (http://www.wales.nhs.uk/documents/cons_doc-e.pdf). This is supported by papers from Psychiatric Services which examine family treatment and those with mental health in their family. They also provide evidence-based practices to families of people with psychiatric disabilities (http://psychservices.psychiatryonline.org/).

Children with a specific condition are supported within family constructed services as Manchester local authority works with children with autism. "Every Child Matters" is an important background to this work (http://www.autismgm.org.uk/).

The Children's Preventative Programme Fund was set up in 2000, in part as a catalyst to move forward inter-agency co-operation and child and family-led preventative services in local authorities. The initiative was developed in 2000 and runs until 2008. The initiative targets children and young people aged five to 13 years who are considered to be at risk of social exclusion in 149 partnership arrangements across all 150 local authorities in England (http://www.dfes.gov.uk/research/data/uploadfiles/RB778.pdf).

DEMOS have set up work with families in Lewisham, Knowsley and Bristol with NEET (not in employment, education or training) young people and parents wishing to engage with their children's learning (http://www.demos.co.uk/projects/userledservicedesigninlocalauthorities/overview).

Family led projects with funding from the Neighbourhood Renewal Fund have been used by a number of housing estates in Birmingham (www.family-housing.co.uk/Community_Regeneration/Working_in_Neighbourhoods/).

Other services such as that from Sure Start and DoH provide family planning services through an organisation called "Spa Spiders" (http://www.doncaster.gov.uk/about/chamber/default.asp?Nav=FPDetail&KDID=2888).

1.4.4 Evidence of family led services for deaf children

In 2001 the NHPS (Newborn Hearing Screening Programme) examined two different approaches (which it had funded) for early support for newly identified Deaf babies, young children and their families. One of the particular interests of the team was to seek to place the parent at the centre of the professional support services and to encourage parent to parent support. Interviews were held with staff that manage and administer the programme and parents from East 17 and North West Regional Early Excellence Project (NWREEP). Professionals who made use of the services were also interviewed. The study indicated:

- The limited strategic impact of both initiatives
- East 17 showed the effectiveness of a truly multi-disciplinary team.

"The service has been a beacon of best practice in demonstrating how a team of hearing professionals and lay professionals can work together to provide a truly family-centred, integrated and seamless service to families with a child with hearing loss…It has also made an

important distinction between this work with parents and the other vital area of parent to parent support. Through its Coffee Morning approach…the parent to parent work at East 17 has grown from strength to strength and provides a model of how such work might be undertaken elsewhere in the country." (p.28)

- The NWREEP has completed successful early work in bench-marking as an indication of the need for Local Authorities to be clear about their starting place and current service provision when providing and developing services for children with a disability and their families.
- This work at least offers some evaluation of the provision – which it deems very successful. The extent to which parents can become the decision-makers is not clear. The expectation still appears to be that professionals will lead but offer partnership. (MRC The Report: Excellence in Early Intervention Pilot Programme The Newborn Hearing Screening Programme (2002-2006))

These reports still retain the service perspective and the evaluation is very much in terms of service delivery rather than family need.

The National Deaf Children's Society (NDCS) operates a system of regional support to families and encourages family to family contact. However, it is difficult to find any evaluation of the service provision and despite perceptions it is hard to know to what extent parents are empowered by their current level of involvement.

The NDCS has supported parents by encouraging them to be representatives in local CHSWGs (Children's Hearing Services Working Groups). The CHSWGs, based in health authority areas, work to ensure that all services designed to support Deaf and hard of hearing children and their families work in a co-ordinated way. Each group includes representatives from health, social services, education, the local voluntary sector and, crucially, parents of Deaf children. It is not yet clear how effective these groups are from the family perspective and we have not yet been able to discover research which evaluates the impact of these groups on family life where there is a child with a hearing loss.

1.5 Conclusions

- There is a major shift in policy and support which also has attracted considerable investment from Government.
- The family services described are based mostly on perceived good practice and are meant to offer initiative where none existed previously. They are therefore created as a stepwise improvement on previous services.
- We are not clear that any of these approaches are truly family-led;
- We are surprised at the lack of recourse to Deaf experts as contacts for the families
- We have yet to discover adequate family-side evaluation of the initiatives.

Chapter 2: Plan of Work

Following a series of meetings beginning in 2005, a group of parents, professionals and researchers, set out to explore the idea of creating an integrated family-focused and family-led set of services for Deaf children and their families in the South West Region of England. The Stepping Stones project was set up to collect the preliminary data which might help to shape this aspiration: in particular to collect and present a set of data concerning services for families of Deaf children in the South West of England by

- Direct contact with the service professionals
- Interviews with parents
- Production of a case study of the existing Family Centre for Deaf Children
- Review of research on family services

This consultation work was to be conducted in a relatively short period of time (six months) to provide a snapshot of existing views. The parents of deaf children participated in Stepping Stones in the following areas:

- Representation on the steering group
- A parent carried out the interviews of other parents
- The parent interviewer was herself interviewed
- The parent chair of the FCDC carried out a review of the Centre, recorded his reflections and made recommendations

2.1 Existing Services

In the examination of existing sources of information, we looked at relevant websites in the South West – all of the Local Authorities, the Primary Care Trusts, Social Services departments and Education departments. This was done from the perspective of a parent looking for information on services and provision for their Deaf child.

2.2 Parents of children in the system now

There were 12 parent interviews in this section of the study. Details on the parents are as shown in Table 2.1. All the parents interviewed were hearing. Because of the short time span of the project it was not possible to create the comprehensive sampling that might have been ideal. We do consider that we talked to parents who might be considered hard to reach – teenage single mother and others who were not involved in the services provided at present – but the overall numbers contacted and the

geographical distribution should be considered only a preliminary examination of the topic. It is important that a more extended study be carried out at the next stage of the project.

Table 2.1: Parents who took part in the study

Parent		*Family description*	*Age of Deaf child*	*Placement*
1	Mother	MFDH	11yrs	South Gloucestershire
2	Mother	MFHD	12yrs	Bristol
3	Mother	MFDD	5yrs 2yrs	Bristol
4	Mother	MFDDD	12yrs 11yrs 7yrs	North Somerset
5	Mother	MD	6yrs	South Gloucestershire
6	Mother	MFDHH	14yrs	South Gloucestershire
7	Mother	MFD	4yrs	Bristol
8	Mother	MFD	7 months	North Somerset
9	Mother	MFHHHHDD	6yrs 3yrs	Bristol
10	Mother	MFHHDD	8yrs 7yrs	South Gloucestershire
11	Mother	MFDH	15yrs	Bristol
12	Father	MFHHHDHD	10yrs 6yrs	Bristol

Twelve parents were interviewed. They were living in South Gloucestershire, Bristol and North Somerset although three sets of parents had moved from Brighton, London and Dorset and one set of parents moved north where their second Deaf child was born. This should not be taken as a representative geographical sample of the South West, although we believe the diversity of views and their extent (the interviews often took 2 hours) indicate that a wide range of parents have been consulted. The Deaf children who are part of these families ranged in age from seven months to 15 years old. In total there were 18 Deaf children in these families. A small proportion of the children had received neonatal screening for hearing (the majority were too old).

2.3 Professionals

There were 7 interviews with professional staff. Details on the participants are shown in Table 2.2. As indicated above, the study has to be considered to be a preliminary consultation only as the selection of participants was limited by the time available for the study and the logistics of organising the interviews. Many more agencies and groups were contacted but due to their professional commitments and priorities, it was not possible to arrange times to meet.

Table 2.2: Professionals who took part in the study

Professional	Gender	Role	Extent of work with Deaf children and their families	Extent of responsibility
1	Female	Head of Sensory Support Services	Major part of job	Management of hearing and vision team work
2	Female	Hearing Support Co-ordinator	Major part of job	Management of Deaf children from birth to 5 years old
3	Female	Acting team leader	Major part of job	Management of caseload
4	Female	Head of school for the deaf	Major part of job	Management of regional resource for Deaf children at primary and secondary level
5	Female	Team leader and local co-ordinator for NHSP	Work with health visitors who work with Deaf children and their family	Train screeners (health visitors) and chair of CHSWG
6	Female	Lead paediatric audiologist	Co-ordinating care of child	Co-ordination and liaison in local authority
7	Female	Paediatric audiologist	Major part of job	Head of paediatric hearing services in local authority

Seven professionals were interviewed - four of whom came from education and three from health. The education professionals were two teachers and two heads of sensory services. The health service professionals were two paediatric audiologists and the team leader and local co-ordinator of NHSP (National Hearing Screening Programme). The professionals came from Bristol, Gloucestershire, Devon and Cornwall.

Two further sets of interviews were carried out by two students attached to the project. These data on fathers and on parents of grown up deaf children are of some interest and

are presented in an expanded report (Dawson et al, Stepping Stones, 2009) but are not central to the main questions here on current provision.

2.4 Case Study of the Family Centre

The case study of the Family Centre was constructed from an analysis of the records kept during the 15 years of the Centre's existence. Minutes of meetings and discussion papers were analysed and an interpretation was made which drew upon the experiences of the researcher (who was also a parent of a Deaf child).

Chapter 3: Looking for Information

One of the most obvious responses to having a deaf child is to seek out information from all available sources. The giving of advice used to be in the domain of the visiting professional, unless the parent wished to spend a great deal of time in libraries. Now it is possible to seek out that information from the comfort of one's own home through the Internet. In this part of the study, we wished to determine how easy it was for parents independently to find information about services in the South West. There have already been research studies of parents and the Internet.

3.1 Internet for Information

Blackburn & Read (2005) examined parental access to information via the Internet. As part of a larger study, they identified responses from 788 parents/carers with disabled children in the UK. They indicate that around 83% of parents have access to the Internet and have used it for information. At the same time, they described a series of reported problems:

- It takes too much time to get information 86% (448)
- Can't find the information needed 85% (435)
- Find websites difficult to navigate 79% (397)

Circumstantial barriers to use included:

- Lack of time owing to demands of caring 57% (332)
- Lack of time owing to other commitments 61% (351)

Their results support the view that the Internet ought to be a major source of timely information to parents and this generally supports government strategy in this regard. However, there are still some major problems in the accessibility and appropriateness of information.

In a study in Australia of parents of Deaf children seeking information after early screening, Porter and Ediripuligge (2007) concluded

> This study confirms that searches for health information on the Internet are conducted primarily by mothers. In the Australian context, there is minimal online information available to families beyond early intervention (page 518).

Of 166 responses to the online questionnaire, 67% were comfortable using the Internet and 89% used it from home. The two most common searches were for parent support groups (55%) and educational options (54%). This was the same no matter the age of the child.

Critical questions from parents were:

> Parent 1). Parents want to find objective information about their options regarding early intervention, education, communication, and technology ("Unbiased information about communication options backed by research findings and information about educational options,")
>
> Parent 2) "Detailed service provider information, i.e. what do they do, how do they measure the effectiveness of what they do," ….
>
> Parent 9). Information about parent support groups, including groups for families of older Deaf children, as well as information for continuing education for parents such as Auslan classes and parent workshops and seminars
> Porter & Ediripuligge, 2007, page 525

The findings in these two reports are fairly clear cut: parents use the Internet and seek specific unbiased information on the possibilities for their children and they want to know how success is measured by the services.

3.2 Looking for information in the South West

As part of the overall review, we examined the publicly available information on websites of all the education, social services (Gloucestershire, Wiltshire, South Gloucestershire, Bristol, Bath, North East Somerset, North Somerset, Somerset, Devon, Dorset, Cornwall and the Isles of Scilly) and all relevant health trusts.

We began by examining the Disability Equality Statements of the Authorities in the South West. Each local authority is required to have a Disability Equality Scheme.

In 2007 a Disability Equality Scheme was published for the entire South West. Brief mention is made of Deaf people in the document. There is also some mention of work for those with a hearing impairment e.g. the provision of hearing aids. (www.southwest.nhs.uk/news/Disability%20Equality%20Scheme%20Board%20Paper%20020707%20Final.pdf)

However the pattern which was to become common throughout this analysis was that there was little explicit reference to Deaf people and it was clear that that families of deaf children would not be able to gain specific knowledge which would aid their child-rearing or family life by Internet searches of the authorities in the South West. Taking the perspective of a parent searching for information on behalf of the child or looking for services which applied to the family, we were frustrated by the complexity of websites and ultimately by the lack of useful information.

There was some variation as can be seen in the notes of the researchers but we had a strong sense that there was a huge gap in information provision.

3.3 Information from the websites

Our primary aim was to map the services which we found in each Local Authority and Trusts throughout the area. However, this was impossible to do sensibly, as the information presented appeared in such diverse forms with different conventions. There were in some cases many activities but they were presented or described in such a way that it was not possible to determine which activities matched which in other Authorities.

We were struck by the fact that relatively simple information was not available. As a parent one might have expected a step by step guide of the process of discovery of hearing loss and a description of the professionals and services which were relevant to the child at different ages. We might have expected that there would be information on the meeting places for parents, their regularity and the expectations for involvement of parents. We imagined that there would be some detailed information explaining what hearing loss was and then what sign language was and detail on the procedures used in that area for achieving success with Deaf children. We should also expect to see some independent evaluation figures of the successes of the services (as of course there is for mainstream services).

Finally, we could have supposed that there would be contact numbers and locations of schools, nursery provision which might admit Deaf children and detail on the additional services in place.

None of these expectations were met. The navigation on the web sites was poor. And we could not help feeling that parents would simply be frustrated in their attempts to find out more about Deafness and the support they might expect for their families. There was certainly no independent explanations of the decision points for families with Deaf children.

There were areas of contradiction or omission – for example where the Bristol City Council has a clear policy of recognition of BSL but there is no mention of it in the sensory services provision for children. The council accepts and promotes sign language but the professional web information for parents offers no indication of this policy.

In discussions with the professionals working in the field, their perception was that most of the information we were looking for would be provided by the professionals in contact with the families. Services for children with hearing loss typically allow considerable person to person contact and it was considered that this was the means of choice for providing that information. Clearly this could lead to a valid and personalised service. However, it seems more likely (after we talked to parents) that information was filtered and tailored to the perceived family situation and would not be as extensive as we would have expected to find if there had been a web information service.

3.4 Conclusions

The study suggests very strongly that there is a need for a family location on the Internet which would collate all information from the South West in a simple accessible format. There is an obvious first step for the proposed new family-led service.

Chapter 4: Understanding Parent Views

The interview responses were written and transcribed, and were analysed using NVivo software to allow the sorting of the emerging themes and the drawing of models as illustration. In the report below several of the emerging themes are explored. These are visually represented where this is appropriate. The analysis tries to represent what parents mean when they discuss certain issues. The first step is to describe the common issues which parents talked about. In a second step we then debriefed the parent interviewer and asked her to reflect on the primary issues from here perspective.

Most of the parents were mothers living with their partners. One was a young single mother another was a father with several other children.

4.1 Learning that your child is deaf

One mother described using the clap-startle technique to self 'detect' the hearing loss by 6 months but it was not confirmed until her 9 month test. Two parents had experienced a caesarean birth of their child and in each case were told by doctors that it was common for babies born by caesarean to have fluid in their ears. In both cases the child was eventually found to be deaf. Another mother had tested positive for German measles and the child could not see or hear properly. Deafness was a genetic characteristic in one family so the parents were not surprised that their two children were deaf.

Many of the parents (mothers) described the shock they experienced on learning of the deafness of their child. One mother said:

> The baby I took to hospital was a different baby from the one I brought home. I now know that I needed to grieve for the baby I lost, but I never had the opportunity. I had to get on practically, but really I needed time to grieve. (Participant 6)

The experience of learning about the deafness of their child had a profound effect on this family. Having Deaf children would affect how some people behaved towards the child and the family.

> Maybe we'd be more accepted now that we have a normal child as well, but as a parent, I don't want to take child A out; other children just stare and make comments. It's not their fault, they're only kids and they don't know any better. (Participant 1)

Another parent talked about the frustration that her child experienced at being treated differently by hearing children. One more parent relates that her child was in a hearing nursery with 30 other children and he changed from being a confident, happy child to an introverted anxious one. This parent described her 14 year old Deaf son thus:

> All through school friendships had been difficult. First year at secondary was fine, but in his second year it all took a turn for the worse. He physically grew, he had hormone rush, and he became more aware that he didn't fit in. He never socialises outside school. He would walk to school with some other boys from our area, but it was hard for him. He would miss most of what was being said and, he told me, if he said "pardon", they would just reply "doesn't matter". He doesn't want anyone to go into school and talk about Deaf awareness - that's a complete no go. He doesn't want to draw attention to his deafness. He's anxious and paranoid people are talking about him. (Participant 6)

The concern that parents expressed in respect of interaction issues was quite common. The main people with whom they were in contact in the early years were audiologists, teachers of the Deaf and, in some cases, social workers. Some parents commented that attending many appointments meant that their Deaf children could not spend time socialising with their peers

4.2 Audiologists

The aim of the Audiology (hearing) service is to provide a full screening, assessment, diagnostic and rehabilitation service for children, with hearing and balance problems. Outreach clinics are provided in support of the Ear Nose and Throat (ENT) Consultants. Audiologists will support children by working with their hearing aids or cochlear implants where appropriate. Hearing assessments and diagnostics are a part of the audiologist's job.

There was a mixed view about the role of audiologists when working with the children: ranging from absolute delight from one parent to dark suspicion from another parent. Some parents did not like the automatic link with cochlear implants (seen as a decision point by parents). As professionals, they could be seen as helping but also may be perceived as manipulating. As the audiologist was one of the first professionals encountered there was a need to obtain information. This information was not seen as independent nor evidence-based . The audiologist (and the teacher) were often members of the cochlear implant team.

4.3 Teachers of the Deaf (TOD)

The teacher of the Deaf is required to make contact with a family with a Deaf child very soon after discovery. Perhaps because the teachers of the Deaf are meant to visit parents at home, they are perceived as having a counselling role. This raises expectations, which this group of parents did not feel were being met.

In some cases, the family views on the visiting teacher of the Deaf role were negative and sometimes hostile. They claimed there were issues of bias and reported the imposition of a model of "me as the helper and you as the person who has to acknowledge the problem" in order to be helped.

In addition, there seemed to be a different experience with teachers of the deaf when the family had been living outside of the area. For example, one parent relates that a teacher of the Deaf in another part of England tried to dissuade the parents from using sign language with their daughter. The parents paid privately for a tutor to teach them sign language. The family later moved to Bristol where the attitude was different. Another set of parents complained about their teacher of the Deaf "up North" who took over a month to contact them again and did not look at the statement of their first Deaf child. When they had been in Bristol with their first Deaf child, the teacher of the Deaf had been "fantastic".

Comments about sign language communication assistants (SLCAs) were favourable as these people were mainly Deaf themselves and could communicate with the child.

Teachers of the Deaf were reported as helping parents with the completion of the parent report/statement of views which were to be presented in the assessment leading to a statement of special needs. This is something of a dilemma for the professional. Direct support to the writing of the parent report might not what would be expected by statutory procedures where the teacher is an employee of the Local Authority and might not be seen as unbiased.

Another parent describes her experience with a teacher of the Deaf in wholly positive terms:

> Before I had reached my front door, I received a phone call from a teacher of the Deaf (tod), and received my first home visit a few days later. The tod gave me information about Acorns - a parents

> group - which I accessed. It was good to find I was not alone in the situation. Since then I have taken on the deafness in a positive way. I say "I'm loving it! I'm embracing it! Bring it on!" (Participant 9)

In both these sections, the underlying theme seems to be one of a desire for independent advice and information which is supported by data on effectiveness of the services being offered. These turn out to be high expectations. The service was not always seen as forthcoming to that extent.

There was then a division between those who had found someone to relate to and others who felt that teachers of the Deaf (in the pre-school) were not effective (interactions change when the child is at school). The extent of satisfaction seems to revolve around individuals and much less around the provision of an ideal service. It would appear that the expectations of those parents who were interviewed were not always fulfilled at this point.

Figure 4.1 indicates what the parents said about the teacher of the deaf. The green boxes indicate a more positive view.

Figure 4.1: Statements about teachers

4.4 Social Worker

Social Services have a statutory role but this seems to work only in crisis mode and many parents seemed to have no special view to express about social work support. In statutory terms, the Deaf child is meant to be assessed and supported by a social worker. In practice, we know that due to social worker case load only those with an additional layer of difficulty are likely to be seen. There is already apparent in the parents' comments, a sense of 'professional overload' which is illustrated by reluctance to meet, lack of perception of positive worth and confusion of roles where the Deaf Sign Language Communication Assistant (SLCA) is considered under the heading of social worker.

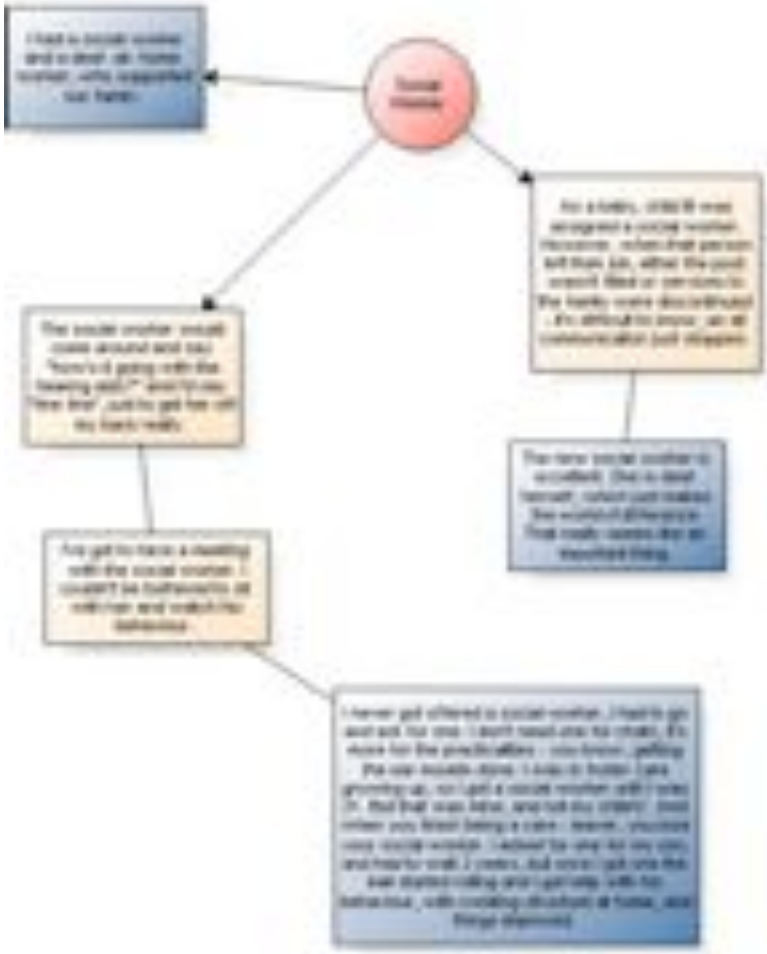

Figure 4.2: Social Worker

Three families reported having a social worker. In one case a second social worker was Deaf which pleased the family. Another parent had been very young when she had had her baby, and had been "in-care" so was used to having social services support.

There was no mention from the other parents about the absence of social services or whether they felt that they needed a social worker. This aspect is quite worrying as the role of the social worker is important in dealing with the personal and emotional development of the child as distinct from the medical and the academic which may be given more prominence in early interventions.

As we will see later in this report, the other professionals commented about the lack of social services input in professional activities surrounding the Deaf child.

4.5 The Cochlear Implant

Another feature of the early experiences of some families is the discussion on the availability of cochlear implants. There has been a major increase in availability of this surgical intervention for young deaf children to the extent that it is more or less routinely offered to all families where hearing aids only provide limited access to spoken language for the deaf child.

Five of the children in the study had cochlear implants. One mother reported that the cochlear implant team were fantastic. Another said that the implant was her son's choice and, although it was not a miracle, he was a lot happier. Some were less positive: a parent described the difficulties in the operation experienced by the child.

> The operation was in October, and it was switched on in December - that was our joke about going to London - the Christmas lights were being switched on, and so was our son's C.I. You have to try to keep a sense of humour.
>
> Then it turned out that they had left something inside by mistake during the operation. He fell out of bed - for the first time in his life - and there was blood everywhere. It was awful, they'd left something inside. I didn't want to do this anymore, but we were already on the rollercoaster, and there was no getting off.
>
> Anyway, he was switched on, and about 45 minutes later he heard something, and signed "noisy sweet". Then we went to see the lights and at the underground he stood back from the line when he heard the train. Then we knew we'd done the right thing, and began to feel very positive. (Participant 6)

Other parents commented on the use of cochlear implants in a more critical way. One parent complained that the teacher of the Deaf (an education professional working for the local authority) was also on the CI panel (a medical service under the Health Authority) which the parent thought should be kept separate from her teaching job. This is a particularly interesting comment as it suggests that at decision points, the parents see independence as most important. However, the whole trend of service provision in special needs is towards multi-professional teams and supposedly 'joined-up' service. The fact that parents felt uneasy about this situation shows powerfully the distinction between the support for informed choice (which has to be independent of the optional services) and the provision of the services themselves (which might be multi-professional).

Another parent complained about parents' group meetings being much more concerned with *hearing* saying:

> Its attitude is that deafness is a problem that we need to try and fix, not that it's ok to be deaf. (Participant 8)

In the pre-school stage, there is a likelihood that medical matters will dominate professional intervention. This does not always appear to be what parents want.

4.6 The Child's Friends and Social Contacts

When a Deaf child is born, the likelihood of the next door neighbour's child also being Deaf is small. Deaf children are distributed widely geographically throughout the community. Significantly they are also distributed in socio-economic and cultural terms. It is likely that none of the parents in any year group of Deaf children would ever meet each other, except for the fact that the child has a hearing loss. The group into which the child is born is not naturally connected socially. This creates some difficulty for the interaction of the children (and parents/families).

The parents described how their children had friends. Some children made friends at school and some friends were hearing. However more parents commented on the child's lack of friends.

> Generally people are ignorant, they forget to bother, just chat, and expect him to get the gist of things. He's a really isolated child. If you compare him with his brother, it's worlds apart. He has no friends in the local community. His only friends are the kids of mum's friends. (Participant 2)

The children who are part of the study range from 7 months to 15 years. This means that they will be at home, in nursery, in primary school or at secondary school. With some of the children their place of education worked well for them as the social focal point but for others there were problems with their peers.

> Last May my Deaf child broke his arm; he was clearly traumatised and it seemed to bring all his fears and anxieties to a head. Not one kid from school made any contact, and they knew what had happened. It's clear, he doesn't have friends. Anyway, from that point he started to become aggressive, verbally and physically. (Mum weeping) My other children have been involved. He says he wants to be dead, that he wants to kill people in our family. If this was a job, I'd have left by now. It's like living on eggshells - you can't live this way. (Participant 6)

The main point made by the parents about their children's friendships was that having a hearing loss appeared to work against the child becoming a social being.

This topic is somewhat complex and is sometimes loosely referred to as the 'child having a peer group'. It is most likely to become an issue when the child starts school (which is also a decision point – see below). Now the geographic distance comes into play if the child is transported to school and the social distance becomes a factor if the child goes to the local hearing school. At this point, it is unlikely that parents have continuation of

home support and there is also no easy means to report from school to home about social interaction (mainly because the school may not have the resources to monitor peer group interaction). The complaints of parents here are very real – the child is in danger of becoming isolated in ways which are quite dangerous to personal development. These may only come to the attention of the services when they spill over into academic problems.

This would appear to be an area where a family-led approach might create a different tier of support.

4.7 The Deaf Child's School

Not surprisingly the issue of school placement affected the thinking of all parents contacted. So much hinges on obtaining the right education and the correct placement. There is some perception that the focus of all the development of the child appears to be on the school and particularly on academic progress.

Six of the Deaf children attend a specialist school for the deaf. Another family was very keen for their child to attend this school but had experienced many difficulties in trying to obtain permanent attendance for him. He is now attends a specialist mainstream school for children with severe learning difficulties for part of the time and a school for the Deaf for the rest of the time. The parent says:

> In my opinion, our area needs a school for Deaf children which has provision for children with additional needs; an SLD class within a Deaf school, much like a lot of mainstream schools have. And then they could all mix at playtime, and the peer group would happen, because they'd get used to each other. There are lots of children in this area going to SLD schools and being taught in English. It's crazy, like an extra hurdle. It's harder for these kids to learn anyway, and then it's being made twice as hard again. Deaf children are isolated anyway, and when they have other needs it's like a double isolation. (Participant 2)

One child had not yet started school and 6 other children attended a mainstream school with a Hearing Impairment Resource Base. Four children attended mainstream schools. One of these children had additional difficulties and the school was allocated 25 hours of additional support. What becomes apparent is that the discussion of the service provision moves from a family focus in the pre-school towards the judgements about the extent of in-school support for the child. Usually the Local Authority applies a formula to this provision based on the assessment of needs. Although the assessment of needs, placement and decisions on support are multi-professional and are meant to engage with

the parents, the reality is that the family itself is not considered as the primary focus – rather it is the needs of the child which are examined. Not surprisingly also, the academic progress of the child is treated as a key indicator of success in the provision.

When we talk to parents of school age children, it becomes clear that in their view, the family as a unit has slipped out of the picture and the personality growth of the child has not been considered at all.

4.8 Fathers

There has for a long time been a concern that the father is likely to be left out of much of the information giving, skills development and general participation.

Figure 4.4 Fathers in families with Deaf children

Figure 4.4 indicates the differences in the views of the role of the father of a Deaf child. The green boxes indicate a more positive view and the yellow boxes a less positive one.

Most of the parents interviewed were mothers. One father made the comment that now that he is separated from his wife he no longer works with his children as everyone deals with his wife. When talking about his relationship, the father said that he and his wife had little time together to build their relationship because all their energy was spent with their children. He said:

> Also their mother spent more time with the children, which meant she became more fluent in sign language, and that affected our balance of power and caused problems. (Participant 12)

The other families seemed to polarise between saying that the father was a marvellous support and that he could not cope with having a Deaf child. Many of the mothers said that having a child who was Deaf created strains between her and her partner. One mother says:

> It's certainly put our relationship to the test; he'd be working all day and want to come home and relax, but I'd have been dealing with child X all day, and that was very hard at times, and we were both struggling, so we'd take it out on each other. (Participant 1)

Some mothers comment that fathers do not have groups to support them or opportunities to meet with other fathers of Deaf children

> not just to learn sign language, but also to moan about their wives! You know, "my wife thinks she knows it all" (Participant 3)

When we discussed separately with fathers, the issues of marginalisation in regard to service provision, decision-forming and interaction with the child are prominent.

4.9 Learning to Sign

Every parent spoke about the issue of learning to sign; however it is not clear to what level they aimed to learn to sign and indeed the extent to which they had achieved their goal. One parent spoke of being at level 3 in BSL, which is an adult sign language assessment. Fathers had difficulty in learning to sign because of their jobs although one father was attending sign classes in the evening and another paid for a private tutor to teach him and his partner to sign. The extent of hearing loss and the hearing help for the child affected the degree to which parents experienced signing. In some cases other members of the extended family learned to sign. One parent said:

> It seemed obvious to bring the Deaf children up with English and sign language, until the family's teacher of the Deaf said it would impede spoken language development. It made me wonder if I needed to change my parenting. You just assume that a TOD is an expert, and accept their advice not realising that they have an agenda. (Participant 10)

This parent had achieved level 3 BSL and was thinking of training to become a teacher of the deaf.

Figure 4.5 shows some of the parents' comments on learning to sign. The yellow boxes refer to learning to sign and the fewer boxes, the green, show a different experience.

Figure 4.5 Learning to Sign

The way in which parents approached the issue of signing was in terms of the availability of particular training and the intended levels. There was no discussion of the nature, quality and family-centred aspects of sign language interaction. The idea which parents seemed to have taken on was that signing was a method which had to be learned. It did not appear that sign language 'was a language' which would naturally develop in the

child given the correct environment and that parent-child interaction in sign would be linked to the developmental stages and contexts in which the family operated.

4.10 Children's Hearing Services Working Groups (CHSWGs)

CHSWGs are based around health authorities, and are meant to bring parents into contact with the co-ordinated service provision. Each group includes representatives from health, social services, education, the local voluntary sector, as well as the parents. The National Deaf Children's Society describes the parents as contributing 'a unique perspective'.

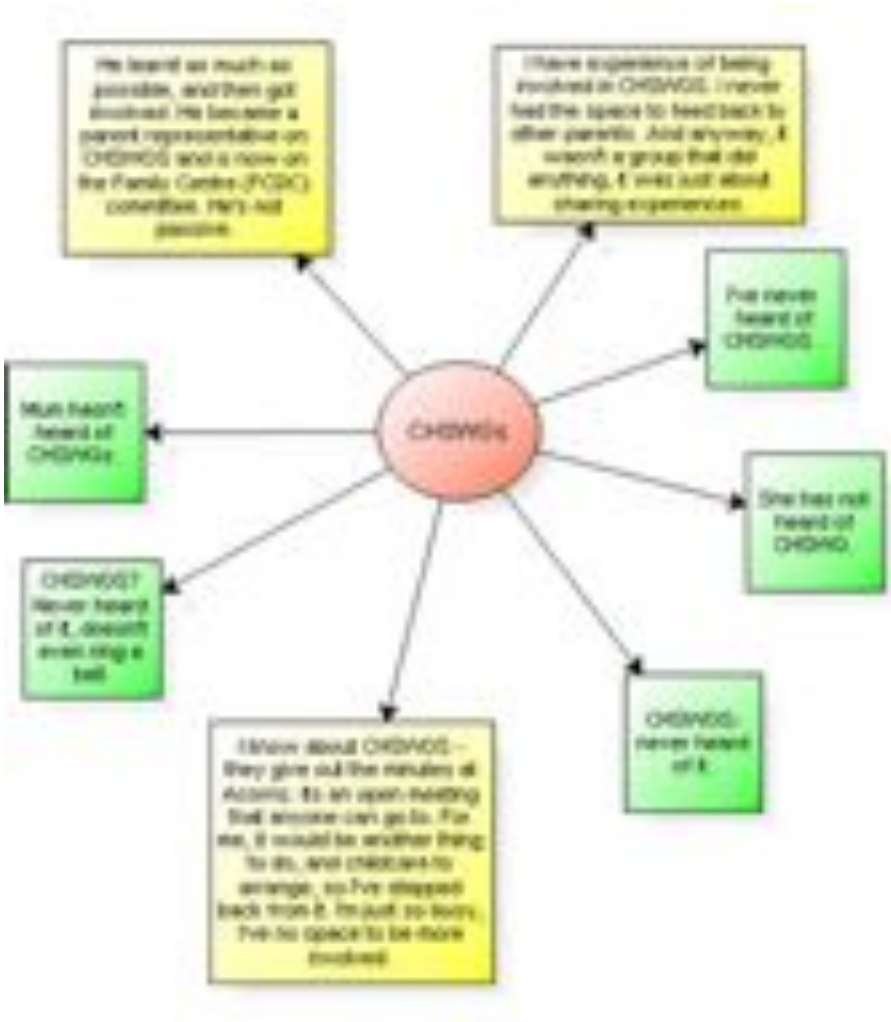

Figure 4.6: CHSWG

It was quite striking that most of the parents did not know of the existence of these groups. In one case the father of a Deaf child made sure that he was part of the meeting; another comments on receiving minutes of meetings and another states that,

although it exists, it was a group that did not do anything. Perhaps significantly, the parents may perceive the groups to be based in health provision at a time when the parents are more likely to be dealing with social, developmental and educational issues at home. The fact that there is only a single representative, seems to locate the exercise away from the reality of home lives in the families. We have not had an opportunity to examine minutes or proceedings of these groups and so cannot comment on effectiveness but it seems to be the case that parents are often unaware of the existence of the group and in any case, may not have time for participation.

4.11 The Family Centre at Yate (Bristol)

The Bristol area is somewhat unique in having for the last 15 years, its own centre created and run by families with Deaf children. This is described in some detail in Chapter 6.

The family centre is highly valued. One of the parents says that she had not heard about the centre, and it was only discovered on the Internet.

A number of parents have described the Family Centre as a lifeline and as way of meeting other families who have at least one Deaf child. There was a difference of opinion between 2 sets of parents with one set saying that Family Centre was for families with young children and the other set saying it was for families with teenagers.

This was one area of the interview where there seemed to be a great deal of enthusiasm by parents. This was not a 'service' – it was a group activity which they contributed to

and through which they met other people. This is indicative of the major desire of families to meet with others with similar experiences.

4.12 A Regional Centre

The central point of the study was to understand whether there was a need for a regional development and how parents might be involved in such a development. The most likely initial image of a regional centre was of a centralised service and a location and some of the comments focused on the advantages and disadvantages of that particular model.

Figure 4.9 Regional Family Centre

Most parents thought that a regional centre would be good for the South West. One parent says:

> I'd like to see a centre that had all the services under one roof. You really need to blur the boundaries for good and effective inter-agency working. You need to be considering all aspects of development, you know, emotional, physical, intellectual and social. "one size fits all" isn't good practice. You need to think of a centre as a toolbox, and families can use the tools they need for their kids to develop well. Maybe you'd have audiology, an ear - mould clinic, a library, educational resources, and a cafe. As a result of that a ready made peer group would emerge. (Participant 10)

However some parents saw some drawbacks to a regional centre, particularly distance, travel and geography. As one parent says:

> I feel ambivalent about a regional centre; if everything is centralised it could make it more inaccessible to a larger number of people. Not everyone has access to transport. Also I'd be worried that local services would be cut, with all the money just going into a building. I don't know, there are pitfalls and advantages; it would depend where it is. (Participant 12)

In spite of saying this, the parent said that he would wish to be involved as long as it was accessible to public transport. A different parent is more positive and reflects the majority view by saying:

> If there was a centre in the southwest, with everything under one roof, it would certainly make things easier. Family weekends, like the Family Centre organise, are one of the best opportunities we have. We just need more of them. It'd be a good idea to have dad's weekends really, (Participant 3)

It seems as if the image which is brought to mind by the words 'regional family centre' is of a service separate from parents but involving them. It might then, somehow detract from existing services or concentrate facilities in a location which was not easily accessible.

The possibility for a wider range of parents to meet was seen as positive yet not an inevitable success in terms of socialisation. One parent expressed concern about linking parents, saying that an assumption that they will get on because of a few shared attributes is a dangerous one. She says that Deaf adults are probably more important than other parents of Deaf children because they give you reassurance that it is completely possible for your child to turn out fine.

The concept of a regional family centre needs more exploration and discussion. It would appear that the concept should not simply be one of a central location and the provision of service but rather a means for family interaction.

4.13 Discussion

This data is diverse. As a small scale consultation it was not designed to create a representative sample of all circumstances across the South West. The timescale and personal resources available simply did not allow this level of family consultation. Nevertheless, major themes have been explored by a parent interviewer in discussion with other parents. Our starting points form the structure of the analysis above and the responses allow us to move forward with some knowledge of the shared experiences of parents. The roles of professionals (health, education and social services) especially insofar as it impacts family life are prominent in parents' responses. The need for

contact and interaction with other families with similar experiences comes out clearly from this computer-based analysis. In the next chapter, we consider the perspective of the parent interviewer reflecting on the interviews-as-discussions with parents and identify the over-arching themes which emerge.

Chapter 5: Family Interviews as Discussion

As well as analysing the content of what other people said there is also important data in the field notes of the interviewer. We asked the interviewer (also a parent of deaf children) to reflect on her own notes and to express her own views of the interactions she had with the families. The following are key points which were chosen by the interviewer.

5.1 Allocation and use of time

This is an issue for some parents. A great deal of time is spent in appointments that parents have to attend about their Deaf child. For those parents who live further away from those appointments, a great deal of time is used while travelling.

5.2 Managing the responsibilities and information

The parents have a lot to take on board. The required shift in perspective (concerning their children) is a challenge. This shift involves many appointments and a change in language. It is difficult to discuss the issues with friends who do not have a Deaf child.

5.3 The Bridge for the Child

The parent has to act as interpreter for her child. The parent feels like she/he is always 'on duty' in support of the child. She/he has to be the link to other people and to the world's experiences.

5.4 Managing other people's reactions

Coping with *other* people's embarrassment about being with a Deaf child is an issue. The reaction of others can be a major problem and often the responsibility for resolving confusion or embarrassment rests with the parent.

5.5 Counselling

In theory, the service provision is meant to offer the psychological support needed by families. However, this is not perceived to be effective. Everyone should be offered

counselling when they learn of their child's deafness. For some people this early stage is traumatic. It was apparent that there were inconsistencies in the services offered.

5.6 Community of Parents

In terms of community-building opportunities, parents meet together because they have a Deaf child, not for any other reason. The Deaf child is the link. The community is *imagined*. Many barriers would need to be broken down to create a real community.

5.7 Community of Deaf children

A community of Deaf children is not automatically created either. Isolation is a huge issue for Deaf children. For many Deaf children social skills are not good; they do not relate to one another naturally and effectively. There is a request for facilitation of the creation of a community.

5.8 Continuing Support

"Early Support" gives support in the early years of a Deaf child but once a child starts school, meetings end. Parents' meetings and family networking may come to a halt as there is no obvious opportunity/provision from statutory services once the child is at school.

5.9 Learning Sign Language

There are enormous barriers to parents when they are learning sign language. These include access to class and the cost of the classes. When this situation is compared with say, the Swedish experience, one can claim that there is no effective support in this country for family access to language. Communication support in a family context is not carried out effectively.

5.10 Mother as caregiver

In terms of families with Deaf children, it is generally the case that it is the mother who is the primary care giver, gatekeeper and manager. This places particular strains on the mother and upsets the usual balance of power and relationship in the family. It may be particularly an issue when there are other hearing children.

5.11 Fathers' role undermined

One of the results is that the father feels remote from the relationship with the child and with the process which surrounds the child. There are no support groups for fathers. This alters the structure of interaction in the family. It is also likely to mean that fathers are not as skilled at communicating with the child.

5.12 Parent Resource and Self-confidence

When parents meet they may feel under pressure to present themselves in a good light. This may be psychological in terms of confidence and ability to speak out in groups but it may also be real in socio-economic and practical terms – e.g. having a car to attend the meetings in the first place. Parents' groups are diverse in these terms. There may also be differences in terms of the competence of the parents themselves. For example, parents with learning difficulties may pretend to understand what is being said to them. The competence of the child may also be a factor. For example, parents with a Deaf child with learning difficulties who has no friends, may have difficulties in discussion with other parents. There may also be a need to put on a brave front; for example a mother who was brought up in-care will be reluctant to say that she can't cope because she has a fear that her child may be taken away from her. As a result of these pressures, parents may need to create a 'front' in contact with other parents. Attending a parent group may not be easy for some parents.

5.13 Professionals

The professionals who come into contact with parents are also a diverse group. Creating an individual relationship is of importance but it appears that this is not always well established. In some cases, it was suspected that the professionals would withhold information because of lack of money for an initiative. They were sometimes thought to speak only of the good points rather than giving a whole balanced view. They could also be patronising. When a child receives a review of his Statement the professionals have to observe the child and give their opinions. Many professionals are not able to use sign language and as a result the Statement is likely to be incomplete and even inaccurate. What is needed in those cases, is a professional who is able to sign.

5.14 Conflict of Interest

There is also a perception among parents that professionals often have more than one responsibility and may be under implicit pressure to recommend or to avoid critical appraisal of a particular programme. This is especially apparent in the case of teachers who work within an education service as advisers/support to parents but also as consultants or even employees of the cochlear implant team. Since parents may wish independent guidance on the options, the impartiality of the teacher as adviser is compromised.

5.15 Involvement of Deaf Adults

One project that seems to work is based in Bristol. It is called Deaf Children at Home. This involves a Deaf adult coming to the family and working with the Deaf child. This was not automatically offered.

5.16 Information Provision

It was felt that the provision of information is variable. It is not automatically provided for families and this can cause problems for the family.

5.17 A new family centre

A centre where all services are included would save time and be a good service. The families felt that a regional family centre would be a good thing. It would act as a wider net for families. The families were generally willing to be involved but said that they have a great deal to work on already. The existing Bristol Family Centre was seen as a life saver although it would be better if there was provision for the whole South West region.

Chapter 6: What the Professionals say

This part of the study examined what professionals said in response to questions from an interview schedule. The analysis is linked to the questions themselves. Description of the participants was provided in chapter 2.

6.1 The work involvement with Deaf children and their families

Most of the interviewees worked with young children and their families. Only one of the teaching professionals worked with older children - teenagers in mainstream school. From a preliminary consideration of the data and the contacts made, it seems clear that the infrastructure for family related services are focused primarily on younger age children

6.2 How the professionals support and guide Deaf children and their families

Family support was usually set up through meetings and discussion groups. Such sessions were meant to be family-centred even though they might not be family-led.

There were a variety of groups for families and their children based at the centre for Sensory Support (Bristol) and a school for Deaf children. As a rule these were mainly opportunities for parents with young children to meet. There were groups for parents with Deaf babies, with Deaf toddlers and children up to school starting age. The school worked with youngsters and their parents at the primary stage.

The health professionals talked of how to support children attending their clinics; this needs tended to be seen in the same area as in the provision of diagnostic tests on babies and children, and evaluating and monitoring hearing aids.

The concern of the health professionals who work with these families was mainly limited to audiology and spoken language.

6.3 Current means of monitoring and evaluating the service

In order to determine the success of the programmes, the education services staff reported the use of questionnaires for parents and exam results for children. They also

mentioned the use of Early Support materials. One Head Teacher reported a range of methods:

> OFSTED self evaluation framework
> Local authority. There are 3 core visits a year which include:
> Child attainment and achievement
> Quality of provision
> Leadership and management
> Pupil and parental feed back
> We are continually evaluating ourselves (Head teacher of school for Deaf children)

With older Deaf children examination results are included in the evaluation and there is a self evaluation framework within family sessions. It is not clear if these evaluations are shared with families or whether there is family specific evaluation.

The health professionals talked of the use of CHSWGs to monitor and audit the Newborn Hearing Screening Programme (NHSP). The national NHSP centre has developed a quality assurance (QA) programme (see www.hearing.screening.nhs.uk) . A major component of this is a system of QA teams visiting all the NHSP sites across the country and running comprehensive evaluations against a range of quality standards. Reports are written and published on their website. Improvement plans are set out and sites are re-visited at a later date to ensure relevant actions have taken place.

The services that are available for families are said to be offered in a fluid and responsive mode; but it seems that objective family-centred evaluation is limited (it is only a part of the way in which services are constructed – being more likely to be driven by the person with the identified problem. It is expected that service provision grows and changes with the needs and expressed wishes of the participants.

6.4 The role of sign language

In some of the education services, BSL is present and is discussed by staff. There are Deaf workers who will sign to children and families during family sessions. Deaf workers will also go to families' homes to communicate with the children and to teach parents how to sign. Staff, including administrative staff, will have experienced at least some of the stages in sign language training. It is a goal that people working with Deaf children will have completed stage 3 of the national sign language training framework although for the administrative staff this would not necessarily be the case.

> We focus on informed choice. We provide BSL for all parents who choose to learn it. There are

> Deaf people within the service. In home teaching we use the Family Sign Language Curriculum (NDCS) and Deaf Children At Home programmes. We also have a Deaf / Deaf group, where Deaf colleagues work with Deaf children in BSL, Deaf language and culture (Hearing support co-ordinator)

The health professionals do not generally use sign language, but may have access to interpreters. There was some mention of other agencies that work with families with Deaf children who use sign, for example, social workers. There is not a sense of this being a major agenda item and it seems likely that the approach to hearing loss places sign language users as very much a minority in the whole client group.

6.5 Initiatives that are currently in place for families with Deaf children

There appear to be variations in service initiatives which is considered to be responsive to the particular groups who are present at that time.

> Groups change so the population changes. On occasions parents mainly have very young babies and at other times they mainly have older children. Some families decide not to attend. The reasons include 1. transport, 2. culture, 3. language. Some families do not want to be seen as deaf. (Head of sensory support service)

The lead in these initiatives for families were usually on the professional side. The take up for these initiatives varies. For example, in one town which supports Deaf children from a number of local authorities in the education of their child, it was said that approximately 35% to 40% of families take part in family groups. A health professional commented:

> This (use of family groups) seems to move in waves. Some families don't want to attend. Social class differences can cause difficulties. There is a very small ethnic minority. There are some Polish and Portuguese families for whom it is difficult to get interpreters. (Team leader and local coordinator of NHSP)

The venue of meetings of parents was mentioned with one education worker saying that a venue in the closest city would be useful for many parents to take part in meetings.

The professional view seems to be that there are fewer parents able/willing to take part in group sessions than we discovered when talking directly to the parents. This may be a result of the different structures offered by services as distinct form those aspired to by parents.

6.6 How families are involved in decision-making with regard to services

Commonly the respondents mentioned the CHSWG as a means of involving families in decisions, although it was not made clear how this would enable parents to be involved in *decision-making*. However in many (most?) cases the CHSWG does not have a parent as a chair and, according to a paediatric audiologist, this can be intimidating for parents when there are many professionals in the same meeting. This is commonly reported in research literature as well and it is usually mentioned in the procedures for setting up such groups. Nevertheless, it still seems to occur as a feeling among parents.

Within the statementing process, parents are involved in decision-making about their child. This is the statutory process and the policy for involvement of parents is quite clear. Parents however, did not report this as being an opportunity in quite the way that the service providers view it.

6.7 Particular issues raised by working with the families

For much of the time, service professionals work with the child and so it may not be obvious which issues relate to the family itself. Typically, the responses referred to parents rather than families.

> Parents report feelings of being overwhelmed by professionals. This is made more difficult when parents are resistant to results. (Paediatric audiologist)

This audiological viewpoint seems also to express some frustration in this (as if it is a further barrier to their delivery) and probably refers to specific contact at point of recognition of hearing loss. Other health professionals did not raise particular issues apart from some parents wanting health services to be under one roof.

The education professionals were more forthcoming in their replies. They raised the issue of good communication systems being available and empowering the carers rather than taking over. There was a criticism about the lack of specialist services for families with Deaf children, and they particularly, pointed out the lack of a social worker.

6.8 Early Support

Early support (www.earlysupport.org.uk) is a new programme which focuses on family working and consultation and provides materials and training to achieve the goals of

integrated family service. It is in a relatively early stage of implementation in the UK (since 2007) and so may not have had a major impact among the parents interviewed in this consultation. The concept of the Early Support Programme is derived from the national service framework standard 8:

> NSF Standard 8
>
> 'Children and young people who are disabled or have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives.'

The Early Support Programme then provides leaflets, procedures and resource to achieve the goals. The material is available on the website. A fundamental principle is of multi-agency working.

The health professionals we talked to, so far, had not been involved in using this; however the education professionals were positive about its use.

> We have been using Early Support for quite a while. It is an important tool, in order to interact with professionals. Some families do not want to use it although the majority do. Monitoring protocol enables parents to see where their children are developmentally and give them confidence when interacting with professionals (as they have done their own assessment). Family Support plans are what we work with. This empowers parents and gives them confidence. (Head of sensory support service)

The Early support programme takes on board most of the issues which would drive a family solution to problems except for the fact that it is still not in the control of the families. There is enormous potential and when it comes with new training for all participants then it offers a much better level of consultation than before. This is clearly an area of growth and one which is expected to be a major aspect of service provision in the years to come.

6.9 Work with older Deaf children

In one city, that has links to a number of other authorities, there is provision for Deaf pupils in a secondary school in which the children will learn about deafness and receive PSHE teaching. The transition team was mentioned by two respondents. The transition team works with pupils over the age of 14 to enable them to move into further education or work when schooling has been completed at 16 years. This is designed to create a liaison with wider groups such as careers service and job centres.

6.10 Work with the fathers of Deaf children

There are problems for working fathers to obtain time away or suitable time off for appointments and attending groups such as CHSWGs. Home visits in the evening are said to be offered. Particular occasions for fathers to meet were sometimes set up, for example, a parents' group meeting in a pub. It was clear from the responses that the professionals felt the part fathers played as an important one but that their part was not a central concern from a service viewpoint.

6.11 Parent-led parents' meetings

Bringing parents together was a challenge for some service providers. The CHSWG was mentioned in this context however it was also pointed out that parents did not lead this. Other groups were more likely to be parent-led if linked to a particular decision point eg newly discovered Deaf babies. However, it seems that inmost cases, service providers have to take the initiative..

6.12 Parent participation in integrated service delivery in the future

The advantages of having a regional focus were seen to be that a larger, more diverse group of parents could use it and there would be more professionals to support the family. It might act as bank of research knowledge for the use of the region.

However, if the regional centre was in one place, it was thought that it might be difficult for some families to reach the centre. This in turn might create more hard-to-reach parents.

6.13 Safeguards and conditions

The creation of any new structure is sensitive in all circumstances and especially one which concerns status and the role conferred by society on those who are trained. Families may be completely new to the circumstances of their child whereas professionals may have considerable experience of work in this role. The decision-making and determination of support might be ceded to parents but the process ought to involve the professionals.

There would need to be an agreement re the working. We need to learn to work together – who

> needs to do what; where roles cross. We would want to avoid tribalism. We would need to build up work between professionals and professionals, and professionals and parents. This would need multi-agency assessment. (Team leader and local coordinator of NHSP)

Another common view (which has a double edge to it) is that when working with families, confidentiality is of primary importance. While this is of great importance to retain information of a personal nature, it might also be used as a reason for not putting parents directly in touch with each other. It had also a further twist in terms of the ownership of the information in that one of the health professionals said she thought it was great that parents would have access to a wide range of provision but the information would need to be given by professionals. The view was that for some parents, the information could be overwhelming and professionals would need to choose the best times for information giving. She finished by saying that such a regional forum would be fine but someone would need to be in control especially for the timing of information giving.

One of the education professionals stated that we needed to look at what families need **locally**, and then determine the need for a regional centre. This is somewhat contrary to the aspiration of parents who feel that there are not enough choices for support and association with other families – hence the need to widen the population group.

Other issues raised included an interesting proposal on funding. The view was expressed that within this funding there would be expenses for parents who attend – ie a means of directly enabling participation.

Another education professional had also picked up on apparent contradictions:

> A family centre would be an ideal way of bringing services and families together. I am a supporter of a family centre as long as it is run properly. It may be seen as pulling in an opposite way to government based community work. Community v. region. The idea could be seen as going against notions of inclusion. (Hearing support coordinator)

Another health professional thought that a regional centre could be set up through existing charitable organisations such as the NDCS. This might be seen as a somewhat traditional style of information-giving, rather than offering decision-making.

> Where would it be? We need to ask the views of local Deaf children's societies. These organisations arrange events. What would be good would be the facilitation of networking between local groups in order that they may share with each other. The chairmen of local groups could feedback to the NCDS. (paediatric audiologist)

One of the education professionals said the following.

> It is not there for Deaf children and their families at the moment. How it would develop is a concern.

These views bring back into focus the professionalisation view that services staff have worked long and hard to reach the level of knowledge and skill in dealing with these children. This should be seen as an enabling factor in supporting parents but there was a need to create the parent to parent networks which would allow the dissemination of good practice; just as long as the information shared was correct.

6.14 Summary

Service providers not surprisingly tend to have a service orientation. They function within a system which comes into play when the parents acknowledge the problem and seek help. At this point, plans of action can be implemented and varying support levels can be implemented. The pressure to work in a multi-disciplinary team nowadays creates new challenges and the overt directives on parent consultation and involvement are setting a new tone for family services. In theory, this should go a long way towards meeting the needs of families and in particular, the new systems in place in Early Support ought to be an enormous help.

Chapter 7: Issues for an existing 'Family-Led' Organisation

Although the motivation for the investigation of parents' views on the creation of a regional centre is new, there already exists a functioning family-led centre at a local level in Bristol. In this part, we consider some of the lessons to be learned from its history and examine the proposals which might be formulated from their experience. The section was written by the current Chair of the Family Centre and the forward proposals come from his perceptions.

7.1 Introduction and Background to the Family Centre (Deaf Children) (FCDC)

The proposal in 1993, for a new 'Centre' came from six main sources[2] in the local area: The Deaf Studies Trust, The Service for Special Educational Needs, The Centre for Deaf People, Avon Deaf Children's Society, The Centre for Deaf Studies and parents of Deaf children. A steering group was established and three main ideas emerged: services should be family focused; parents should be empowered to manage service provision; and Deaf people themselves were considered to be a critical component of any future provision.

7.1.2 Family Focused Services

In presenting the case for the development, some important points were made:

> 'Our research tells us a lot about family adjustment and shows that it is only when the family chooses to adapt that the real benefits come for the Deaf child.'[3]
>
> '…. it is in the home where the child spends most of his or her time and where the major socialisation (preparation for society and adult life) will take place.'[4]
>
> For the first time, the family will be the focal unit. This means that the Centre will be open to families of Deaf children from discovery to the teenage years.' [5]

It was generally agreed that existing services in the early 1990's were too 'child' focused and that this was to the detriment of the family as a whole. Such child centred service provision was seen inevitably to lead to fragmented services because different agencies

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[2]Information taken from a Family Centre Document presented to 'Special Meeting of the Deaf Studies Trust' 14th April 1994

[3]Family Centre Document presented to 'Special Meeting of the Deaf Studies Trust' 14th April 1994. Page 3

[4]Family Centre Document presented to 'Special Meeting of the Deaf Studies Trust' 14th April 1994. Page 1

[5]The Trust for Deaf Studies Report AGM 1994

only provided support for relatively short periods of time (linked to the chronological age of the child. It was, therefore, more difficult for families and Deaf children to build and maintain good working relationships with 'professionals' as personnel routinely changed as the child grew and journeyed through the various stages of their life – pre school, nursery, primary school, secondary school and perhaps college.

The steering group emphasised that the one 'constant' in a Deaf child's life was his or her family. Therefore it followed that provision should focus upon the family and be fronted by a single organisation which, while interfacing with other service providers, would provide constant support to families throughout the entire period from when a child is recognised with a hearing loss until the late teenage years.

7.1.3 Empowering Parents

> Parents are vital. Parents should be partners.'[6]
>
> 'The emphasis is to be family-led as the priorities for easy communication at home and service choice will be maintained by the families who are involved [7]

It was also felt that the interests of the family could only be met by ensuring that parents were given a greater role and a greater say in how the family would interact with support services and professionals. One way of ensuring this would be to establish an organisation with a democratic structure that was heavily weighted towards parents themselves. From the very beginning the aim of the steering group was to establish a parent-led organisation and to ensure that parents themselves were fully empowered.

7.1.4 Deaf Professionals and the Deaf Community

Through all of the early documentation there is a firm commitment and belief that Deaf people themselves, both professional and non-professional, should have a direct and highly visible role within this new organisation. Research conducted by the Centre for Deaf Studies led, in 1990, to the establishment of a service whereby Deaf adults or 'Sign Language Communication Advisors' (SLCAs) would visit families with children who were newly discovered as being deaf. The primary role of these SLCAs is to advise on

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[6]Family Centre Document presented to 'Special Meeting of the Deaf Studies Trust' 14th April 1994 Page 1

[7]The Trust for Deaf Studies Report AGM 1994

communication methods within the family. However a Deaf role model would invariably have a far greater role than this and a much larger impact than simply teaching communication methods. Some of these are:

- It is a non-formal and relaxed approach to de-mystifying deafness for parents and siblings
- It gives parents and siblings access to a wealth of knowledge and experience of being Deaf
- It sends a strong positive message that Deaf people can, and do, succeed in the work place

The success of the 'Deaf Children at Home Project' and lessons learned from it, as well as knowledge obtained from Deaf people themselves were fed into the FCDC at an early stage and it was a fundamental principle upon which the FCDC was built. These services were focused on the relatively small number of families who had Deaf children with a profound to severe hearing loss and who were likely to acquire British Sign Language as a first language.

7.1.4 FCDC Services

The intention was to establish the FCDC as a central point for all families with children with a hearing

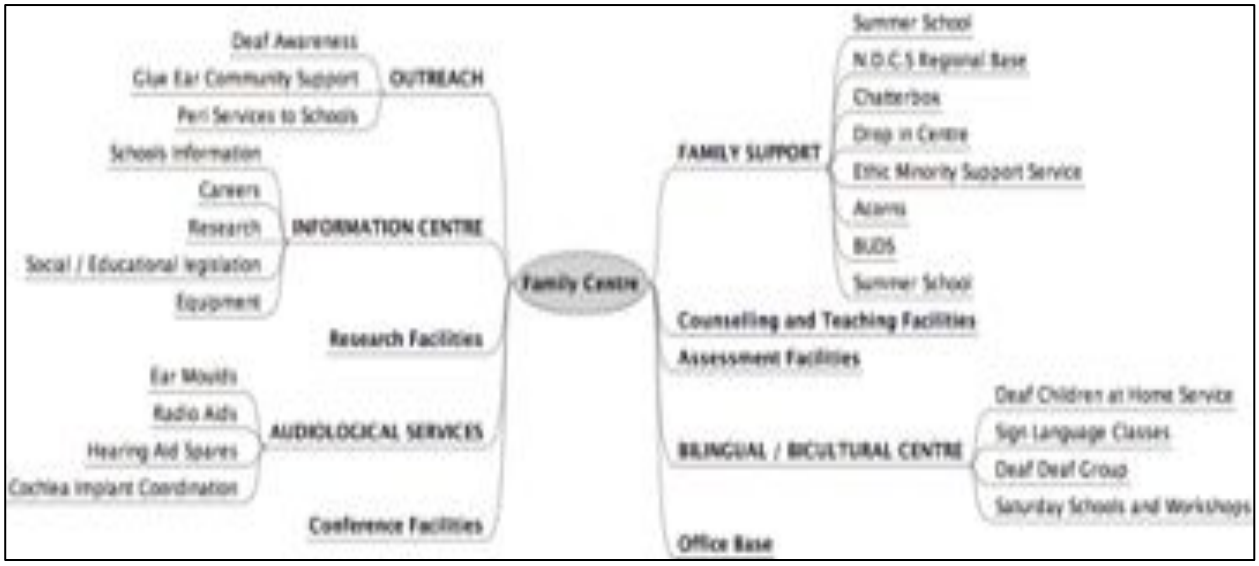

Figure 7.1 Family Centre as a one-stop shop

loss. It was an attempt to provide a family friendly interface to the myriad of services and professionals that existed, and it was also an attempt to create a centre where parents and carers could meet, discuss, become empowered and shape the future of service provision (Figure 7.1).

By liaising directly with all stakeholders the FCDC would be able to coordinate available services more effectively and ensure easier access for families with D/deaf children. Further, the FCDC would be able to identify where extra services were needed and either provide these directly or work with other recognised bodies to do so. Many of the services outlined in Figure 7.1 were already provided by organisations such as the Centre for Deaf People, the Avon Service for Special Educational Needs (now the Sensory Support Services), the Audiology Department and the Centre for Deaf Studies.

7.2 FCDC Structure and Constitution

7.2.1 Structure

Figure 7. 2 – Original Management Structure[8]

The vision of the steering committee had to be packaged within a written constitution and an organisational structure had to be developed to allow this vision to be realised. The structure that was decided upon is shown in Figure 7.2.

[8]Taken from 'Guide to the Family Centre' (Pp 3 May 1996)

The structure allowed parents and professionals to work together whilst 'protecting' and 'recognising' the 'family-led' ethos without alienating professionals or other relevant organisations.

7.2.2 The FCDC Constitution

The roles and responsibilities of each of the committees and components in Figure 7.2 were clearly skewed in favour of parents and carers to try to ensure that the FCDC remained family led,

The constitution states that only parents and carers of Deaf children can become full members and therefore, have the power to vote.

The steering committee would have realised that even the best intentioned and well-meaning professional[9] would have an 'unfair advantage' and undue influence over most parents if each were to have 'equal' status, or say, in how the FCDC should develop. This has nothing to do with exceptional intelligence but rather attests to the fact that professionals are likely to be better informed, be better educated, have more confidence, have better debating skills and be more emotionally detached than a parent.[10] They are also being paid to work in the area of deafness and have therefore, more time and better access to resources than the average parent or carer does.

Whilst striving to ensure that parents' voices are heard the FCDC also tried to ensure that professionals and existing bodies did not feel undervalued, excluded or threatened. A project officer would liaise between the Management Committee and all relevant bodies, acting as a conduit to channel views and ideas back and forth. On occasion, professionals and parents would have the opportunity to meet face to face either at Management Committee meetings (when invited) or workshops.

The blueprint for the FCDC was laid out in the draft constitution which was ratified at the first AGM of the FCDC in 1993. Here are some of the most important points:

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[9]Assuming that the professional in question is 'Deaf childless' as it were.

[10]Of course, these are general observations and there are numerous parents of Deaf children who can also be a 'professional' and carry most, if not all, of these attributes. Also, these attributes are not to be confused with intelligence and the people who possess them should not necessarily be given too much status as a result of having them.

"The Objects of the Centre are:

to further the social well being, development and education of all Deaf children and their families….;"

The emphasis here was upon a holistic approach to assisting families. Families with Deaf children should not be thought of as a unit outside of its' social context. To further the 'social well being' of a family allowed for a very wide remit in terms of support, anything from direct financial assistance right through to emotional counselling, loaning a DVD or a good book. There is also an underlying understanding that the family will grow and change as the child becomes older and that this 'development' will benefit from 'education'. There is a very strong purpose here which aims to empower families through education.

- "to provide a base for families and carers of Deaf children to discuss, to meet, to interact freely with professionals and to have access to materials, information and training as required;"
- "to provide some support, training and information in languages other than spoken English, including British Sign Language, and to facilitate contacts between families and Deaf people;"

This is a crucial component for deaf children born into hearing families.

Deaf children become Deaf adults, and as simple as this statement is, the significance and implication of this seems to be enormously understated by many professionals, parents and government bodies. It seems that many Deaf teenagers and adults are drawn towards the Deaf community even if they did not have the opportunity to do so as children. Community membership and the sense of belonging are enormously powerful motivating factors and are important in what defines us social beings. The Deaf community is continuously replenished with young Deaf adults and children from hearing families[11] and of course from Deaf families. There is no reason to expect this pattern to change dramatically in the foreseeable future and as such, facilitating contact between hearing families and the Deaf community is a very important component of the FCDC.

…the Centre shall have the following powers:

- to promote, encourage or otherwise undertake organised research into the effects of deafness and the family, and to publish the useful results of such research.
- to **promote and encourage the education and training of professionals,** (my emphasis) students and other persons for the furtherance of the education and support of the families of Deaf children;
- to arrange public meetings, lectures, conferences and seminars for the consideration and discussion of problems arising out of childhood deafness and the family;
- The Board of Directors may employ staff to carry out the work of the Centre

[11] A much quoted figure is that 95% of Deaf children are born into hearing families (Conrad R, 1979, *The Deaf School Child*, London: Harper & Row).

It is clear that the starting point for the Family Centre was a comprehensive integration of existing service but driven by family needs.

7.3 Activities and Outcomes

During the last fifteen years the FCDC has provided a wide range of activities for families with D/deaf children. These have generally been well attended and although no figures exist for the numbers of beneficiaries it is clear that the FCDC does have enormous support amongst families throughout Bristol, Bath, North-East Somerset and South Gloucestershire. The most popular activities provided are the grandparents' sign classes (at one point there were three classes simultaneously which still had people on the waiting list) and the annual family weekend trips. Now in its seventh year the weekend trips regularly attract over 50 family members with the last one attracting 70. Below is a non-exhaustive list of some of the past activities:

Sign classes:
Parents
Siblings
Grandparents

- **Workshops:**

Your Deaf Child and Television
Bilingualism
Storytelling
Getting Your Deaf Childs' Attention
What is Sign Language?
Supporting Your Deaf Child with Reading at Home
Information Technology
Deaf Sports
Drama (4 days)
Asian Arts
Stay Safe

- **Training and Education:**

Deaf adults for Respite Care
Deaf Awareness
Cycling Proficiency
Swimming
Filming and Acting
Circus Skills
Football Training
Karate
Dancing
Dry Slope Skiing

- **Entertainment**

Family Fun Activity Weekends (seven)
Signed Cinema
Cinema Club (silent Movies)
Bristol Zoo
Pond Dipping
Adventure Playground
Park Picnics
Ice Skating
Football
Go-Karting
Trampolining
Theatre (annually)
Thorpe Park (Fun Fair)

- **Home Services**

Reading support
Counselling
Sign Support

- **Outreach**

Support for after school club in city farm
Support for local brownies and cubs

A recent evaluation of the FCDC was conducted by the Bristol Children's Fund (January 2008) which interviewed parents, reported on the value of the Family Centre.

Seventy percent of parents agreed that the support of the Family Centre had helped reduced stress levels in their family.

Parents Comments:

"It's good for stress levels as it provides a chance to meet up with other Deaf children and also for them to see that there are other children with similar needs."

Sixty-five percent of parents reported that the activities at the Family Centre had been good for their children's self-confidence.

Parents Comments:

"Brilliant for his self-confidence – he gets to meet Deaf people. It's hard for him to socialise with other [hearing] children in other situations"

"X is an only child and putting her in contact with other Deaf children was really important, it's been absolutely great for her confidence, I don't think she would be the person she is without that now."

Fifty-nine percent of parents felt the services and support of the Family Centre had helped improve family relationships.

Parents Comments:

"His grandparents also did the signing class and it really helped them to have a better relationship with their grandson"

"The Family Centre provided sign classes for my dad, so that now he can communicate with his granddaughter, which was a really positive thing. Over the years their relationship has gone from strength to strength – they have a really good relationship now"

Seventy-one percent of parents felt the services and support of the Family Centre had given them a better understanding of their child/children's needs.

Parents Comments:

"The support and advice from the link worker has been very valued"

"Deaf cultural support has certainly made a difference"

Eighty-seven percent of children and young people told us that they had met friends through the Family Centre activities, with 75% getting to know more Deaf children and 75% getting to know more Deaf adults through the Family Centre.

Seventy percent of parents stated that becoming part of a Deaf community and getting the opportunity to socialise, share experiences and have access to a support network was one of the most important benefits of the work of the Family Centre.

Parents Comments:

"The Family Centre structure has enabled families to maintain and develop relationships with other members of the Deaf community. This provides support networks, sharing of essential information and a community. Please continue this service – it is valuable and appreciated."

These responses indicate the strength of feeling among those who have participated.

7.4 Lessons Learned and ways forward

When the FCDC was established the intention was to create an organisation that would be 'parent led' and this was achieved by ensuring (within the constitution) that all effective power would reside with the voting members (i.e. parents and carers) of the Management Committee. The Management Committee would decide upon all aspects of the FCDC including; planning, policy development and the recruitment and management of staff members.

However, over the years it has been (and still is) very difficult to recruit and retain a critical mass of parents to sit on the management committee and it even more difficult to find parents who want to become office bearers. Whilst the majority of MC meetings are quorate, a significant number are not and this has a direct effect on the successful functioning of the FCDC both in very obvious ways and also in more subtle, but equally damaging, ways.

It has often been unclear as to the exact role that the Management Committee has in relation to FCDC staff and this confusion seems to be made worse by the fact that office bearers (Chair/Vice Chair/Treasurer) are usually the line managers of individual FCDC staff members. Hence, if the executive decision making body is not functioning properly

it has an immediate effect upon FCDC staff members. Not only is it incorrect to assume parents of a D/deaf child would necessarily have the appropriate management skills, but also there is a structural fault-line that needs to be addressed. The FCDC are currently undergoing an in-depth review on this very question. In this short review, justice cannot be done to the complexities and multitude of variables that conspire to stop an organisation being 'family led' but the main issues are listed below with a very brief note to each point made. What is needed is an in-depth discussion on each of these points before any future 'parent-led' organisation is established in the South West through the Stepping Stones initiative.

1. The executive body (Management Committee) is not the right body through which to empower parents.
    - The daily business of running an organisation is very time consuming and often tedious and bureaucratic. The executive body must, by law, deal with the minutiae of running a registered charity and this can effectively eclipse and bury any innovative ideas or spontaneous discussions that might otherwise develop from a group of parents. This inevitably means that MC meetings are generally considered to boring 'duty' one must fulfil rather than a place to meet, chat and find mutual support.
    - Because the MC only meets once a month MC members become increasingly dependent and reliant on staff members for the effective management and running of the organisation. This is further compounded by the fact that staff members are generally permanent whereas the MC has a predictable and steady turn-over of parents. This leads to a situation where staff members become more knowledgeable and more empowered than parents because they deal with funding bodies, local authorities, service providers and families on a daily basis and MC members do not. This inevitably leads to misunderstandings. On occasions staff members feel frustrated that key decisions are either not being made or are, in their view, being made incorrectly. It also leads parents feeling inadequate and apologetic as they empathise with staff members but still find it difficult to carry out their roles as a trustee fully.
    - Generally, parents of D/deaf children do not want to become managers or take on the extra responsibilities and pressures associated with being a trustee but they do want to be listened to, to be able to affect change within an organisation and to benefit from being involved with an organisation.
    - There must be a 'philosophy' or vision that can excite and galvanise parents, a vision that is prescriptive, flexible and inclusive and which continues to be evolve as we learn more from parents and professionals alike.
      The FCDC has a vision but it is too generalised to fulfil this function. It means that staff members and individuals within the MC have no common banner.
2. Parents of D/deaf children should not be line managers and office bearers.

- This concentration of power is especially unwise in the context of the FCDC because it has nearly always been the case, that a parent with a newly recognised Deaf child is elected at the AGM to hold the position of Chair or one of the other important office bearer roles and there is a strong argument that these are the very people who are least qualified or suitable to take on this responsibility.
  parents are not a homogeneous group - especially in the context of deafness because of the very small numbers of people involved[12]

Figure 7.3 Family with a deaf child

As can be seen in Figure 7.3, the only uniting feature for families is the presence of a deaf child. However, there are three groups here.

1. deaf children with Deaf parents/carers
2. deaf children with Deaf parents/carers (non signers)
3. deaf children with hearing parents/carers

This third group then divides along audiological lines:

1. Hearing parents/carers and children with profound/severe loss

[12] This is an interesting question and one that unearths quite a number of issues. First of all, even if parents are not a natural homogenous group, it is entirely reasonable to argue that they should be - if only for the interests of the D/deaf child.

2. Hearing parents/carers and children with moderate/mild loss

The first group can be broadly differentiated by their preferred mode of communication - into:

- Those who decide to use sign language within the home
- Those who choose to use speech within the home

Of course there are overlaps and these divisions are only generalisations *but* it is useful to at least have some understanding of the disparate groups that are thrown together once a deaf child has been recognised.

Of course, those families who choose sign language are more likely to have contact (as a family) with the Deaf community and Deaf individuals - likewise those who choose speech as their primary communication method within the home are less likely to have contact with the Deaf community and/or with hearing families that use sign language.[13]

It might appear, from Figure 7.3, that there is far more to divide parents and carers than there is to unite them but there is a very strong connection that often gets overlooked. It is perhaps ironic, that it is the Deaf community itself that could possibly be the catalyst for uniting (in a very real way) these separate groups. Ironic because for many hearing families the Deaf community is an 'idea' or construct that is considered as a potential ally or foe.

For most hearing families with a newly recognised profound or severely deaf child there is a vague understanding that the Deaf community exists and as parents and carers learn more about deafness that vague understanding relatively quickly becomes crystallised into a simplistic but powerful rationalisation that can be extremely divisive.

Many of the divisions in Figure 7.3 are not politically or emotionally charged and should just be accepted as 'fact' -for example, there is obviously a world of difference between a child born into a hearing family who has a mild hearing loss or 'glue ear' and a profoundly deaf child born into a deaf family or into a hearing family.

The most divided and emotionally charged group are the relatively few families who have a profound or severely deaf child and have to make a choice about which

[13] Add to this the very sensitive issue of cochlear implants for D/deaf children and the very powerful emotions it raised in all groups.

communication method to choose and whether to accept the child as being a potential 'member' of the Deaf community. This inevitably spills over into other issues, such as, whether a child should be given a cochlear implant or not or whether the child should attend a mainstream school or go a Deaf (often boarding) school.

It therefore might be concluded that these disparate groups cannot be united to lead an organisation but that would be missing the point. The Deaf community itself could conceivably be the catalyst for uniting these groups and the reasoning behind this is the simple fact that the Deaf community is made up of people from most, if not all of these disparate backgrounds.

It is possible to unite these disparate groups if there is a shift in political thinking, one which moves away from simplistic and divisive criteria towards a more open and inclusive discourse which has the Deaf community at its centre. The Deaf community needs to be more realistically presented and defined as including members from all of these disparate groups.

7.5 Discussion and Recommendations

The FCDC has, despite the problems mentioned earlier, functioned well now for approximately 15 years and has throughout that time assisted families with a wide range of needs and in very different circumstances and will continue to do so in the future. However, establishment of a new regional service will, at the very minimum, require a new philosophy, one with an emphasis upon 'happy families' and which identifies the core elements that can help make this happen.

If services are to be family focussed then a better understanding of these families is needed; we need to ascertain the 'common' needs or desires. We also need to personalise the service and ensure that everyone feels that they are being listened to (whatever their issues) and that they are important.

So what are core desires or needs as regards a family with a deaf child?

These core elements may be as simple as:

- access to language at an early age *(all the family but primarily the D/deaf child)*
- fluent and easy communication within the home and between family members *(all the*

family)

- peripheral knowledge about their Deaf child or sibling and appropriate interaction techniques including such things as how to get a Deaf child's attention, how to use subtitles, textphones, videophones etc *(hearing family members)*
- emotional support *(all family members)*
- cognitive 'milestones' reached at an appropriate age (*D/deaf child)*
- educational 'milestones' reached at an appropriate age (*D/deaf child)*
- social 'milestones' reached at an appropriate age (*D/deaf child)*
- happiness *(for the whole family)*
- a feeling of inclusion within the local community *(for the whole family)*
- a feeling of inclusion within the extended family *(for the whole family)*
- a feeling of inclusion within the Deaf community *(for the whole family)*
- economic stability
- property/housing stability
- vacations
- socialising with friends and family
- socialising with D/deaf people

The importance of family cannot be overstated and in general families will do everything in their power to ensure that they are happy. The list above is obviously not complete and it may be expected that there could be fundamental differences between lists written by Deaf/hearing families with no Deaf children, to those written by Deaf/ hearing families with children with a hearing loss. [14] The point here is that offering family centred services requires an understanding of which core elements should exist to allow for the possibility of a 'happy family' and to determine what core elements are in danger of being neglected or lost altogether for a family with a Deaf child.

A developing regional centre should have an ideological framework. This framework should have a number of elements but some of these could be:

- A simple and easily identifiable vision that will appeal to vast majority of parents with D/ deaf children, whatever their child's level of hearing loss.
  A vision that outlines a 'path' that is as flexible as possible because no one can be entirely sure what will work best for any particular child or family
  A vision that has core beliefs that unite, rather than divide parents
  A vision that involves and encourages an element of 'education' and discussion for parents who will eventually form the core around which the rest of the organisation will hang. Sensitive issues such as those exposed by the sign language versus oralism debate as well as cochlear implants need to be debated and discussed among parents.
  If a child is recognised as being profoundly hearing impaired then the first step is immediately offer the family access to sign language and to Deaf individuals

[14]In fact, from reports of parents who have 'disabled' children there are obvious parallels with those families with Deaf children.

(professionals) and Deaf parents.
At the beginning all parents are united under a common theme – "we are parents, we have a young baby and they are D/deaf or hearing impaired. There's much in common upon which we can build". A short way down this path ALL parents are given access to an informal, fun and interesting forum group which involves sign language Deaf role models (both oral and Deaf)

7.6 Conclusion

In establishing the FCDC the steering group had a vision that involved a place (or space) where professionals (both Deaf and hearing), parents of Deaf children and members of the Deaf community could meet and share knowledge. The establishment of this neutral space must be a priority for any future service provision.

Many parents have been appalled by the advice and views that have been expressed to them by professionals and this area of professional / public interaction is exceptional in creating such a great deal of anger and emotional stress. It would be unfair to lay all of the blame for this situation on the professionals' doorstep as it is a particularly peculiar aspect of society that most Deaf children are born to hearing parents. This fact alone creates a situation that is extremely difficult for professionals to deal with.

For hearing parents having a Deaf child immediately brings a whole range of issues to the fore which may have very little to do with deafness per se but may have more to do with their political convictions– how they view the world, their open-mindedness, their views relating to minority groups, to disability and so on. Add to this their fears, concerns, confusion and anxiousness relating to the constant idea that 'time is running out' and it's no wonder that parents, especially in these early years, are so volatile.

Of course, professionals too have their 'world-view' both as individuals and to a lesser degree as a professional body; they have their own agendas, which need to be scrutinised and if necessary challenged.

Deaf adults themselves also have experiences and ideas that provide a unique perspective on being a Deaf person in a mostly hearing world. There will be emotional baggage and issues that may be fresh in the memory and may still cause pain. Being bullied, ignored, denied the right to use sign language in school, unable to influence or have a say in the field of deafness – it goes on and on. There is still an enormous amount of anger and despair among many Deaf adults and teens and relationships

between hearing people and Deaf people can be extremely volatile and damaging. These issues and sensitivities should not be ignored but should be discussed.

A neutral space is needed where hearing parents, professionals and Deaf adults can share their views and ideas, openly and without fear of repercussion.

8. Summary

Government recommendations for parents to actively lead and shape the services they receive are based on limited research evidence. This consultation included both "easy to reach" families and those who were much less likely to join groups whether because of the distances to travel or because of their feelings of social distance. Parents' views on the vision a family led service with parent to parent support (as configured in East 17 and NWREEC projects) were addressed although the semi-structured interview format, allowed the parents to describe experiences and attitudes which they felt were more significant in this context. Based on these experiences and the needs expressed, there is a clear directive to take further the concept of a regional facility or centre which is parent-led.

The consultation process also revealed concerns over a range of other issues that had not initially been the primary focus of this project. These concerns were important and strong themes emerged that were common to all areas of the consultation process: the steering group, the interviews with parents, the reflections of the interviewer and that of the parent chair of the FCDC.

Perhaps the most significant point which comes from this consultation exercise is that parents who have a Deaf child, do not suddenly embrace 'Deaf-family-ness', where the sole focus is Deafness, to the exclusion of all other aspects of life. By this, we mean that they do not become a single common identity which allows them to be treated as a single community of similar experiences. It is true that for many, the discovery of hearing loss in the child prompts a huge shift in expectations and promotes very active engagement with services and information sources. It can produce anger, frustration, excessive energy and a drive to 'find out the truth' about the problem. Yet at the same time, the families retain their base in the 'real world' of employment, other children, family relations and socio-economic circumstances.

A family centre (as might develop from this work) cannot assume 'Deaf-family-ness' as the basis for the creation of the centre. Parents (and there are also major differences

between fathers and mothers) continue to be different from each other, with different capacities, knowledge and skills. A family-led centre cannot assume that parents have 'time' to devote to the management of a centre.

In fact, it seems more likely that parents will form the Board of Trustees of such a development but will not themselves be required to manage the conduct of the centre. Is this part of the summary? Maybe the summary happened in the report in brief at the beginning. Maybe this section needs to be called "Discussion on the consultation with families" However, it has been indicated that parents of grown-up children may be a significant source of expertise and it is likely that from this group, will come the managers of the centre.

There is a general approval from all those interviewed for the concept. There are also concerns about how to deliver on a regional basis – due to geography and travel constraints. A regional centre would need to be a fluid concept which may have a resource base centrally, but extensive local contacts and activities.

9. Recommendations

Clearly, the progress of a family centre for the region will be determined by the availability of funding and by the extent of engagement by existing service providers in education, health, social services and the voluntary sector. Nevertheless, it may be of value to set out some of the components for that development and the way in which it might be approached.

We consider that it is likely that a regional centre will be created in stages with funding for pilot development and for implementation of specific components. We propose:

1. Regional conference for parents to discuss the report and its possibilities
2. creation of a regional information portal online
3. setting up of regional pilots on specific issues with underlying parent-driven/ parent-led approach:
   young mothers workshop
   Young Deaf sports
   early parental experiences – sharing of strategies for putting the child to bed, discipline, etc
   technical seminar series – use of the Internet, videophones, text messaging, interpreter services
4. Liaison activities – discussions with statutory bodies across the region, discussions with parent groups across the region (including NDCS)

5. Family database – closed membership of families allowing them to contact each other
6. Ongoing family conference to discuss progress in each of the above areas
7. Commissioned research – on specific topics of relevance to the family centre development process

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