



Open to All?

National Service Framework
Consultation with Parents and Carers of
Children in Special Circumstances

Summary Report
December 2003

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EXECUTIVE SUMMARY

Introduction

The Fostering Network Wales held five consultation meetings across Wales which were attended by a total of 75 parents and carers. The meetings considered current services and what participants wanted for their children in the future.

Common Themes

Participants welcomed universal services, free at the point of use.

Variation in services received were felt to depend on:

- Individual workers
- Rurality
- Economic factors
- Assertiveness of parent/carer
- Membership of a disadvantaged group (including minority ethnic groups)

Parents and carers would like to see their children receiving well coordinated services, easily accessible and available equally to all groups. They would like good information about services for themselves and their children. They would like services to be well resourced and well staffed – with child friendly people.

Health Services

General Practitioners, Health Visitors and dentists were all valued. However, as with all services, participants commented on the variability between staff. Access to referred services was felt to be dependent partly on who you are and how hard you push rather than simply being based on need.

Inconvenient appointments and poor coordination within and between services causes problems, as do lengthy waiting lists and waiting times. The lack of sufficient NHS dentists and Children and Adolescent Mental Health services were identified as gaps.

Social Services

Although considered to be well intentioned, social services were often perceived to be unhelpful. The turn-over of staff and their inexperience are problematic. Services are delivered too late and staff are inconsistent. Minority ethnic groups felt that they received less services than others or that services were culturally inappropriate. Bureaucracy and stigma were associated with social services.

Parents and carers wanted:

- information for themselves and their children about available services and how to access them
- a high quality, stable staff group who spent time with them and their children
- thorough child protection services
- a care system which ensured that each child has a worker who knows them and that services are well-coordinated
- improvements in foster care
- services which are equally available to all and are culturally sensitive

Education

Generally, schools were felt to meet the needs of children and to have the welfare of children at heart. Children looked after could have variable experiences from receiving sensitive help to outright discrimination. Receiving recognition and help for special needs can involve a 'battle'. Education was felt to have improved in terms of respecting black and minority ethnic issues although there is room for further improvement.

Participants wanted a local, inclusive education system which could be tailored to individual needs, with suitably experienced staff and adequate resources.

Leisure services

Leisure services were acknowledged to be important but their use was restricted by cost, by lack of services in rural areas and by deficits in transport systems. Some services did not meet the needs of some minority ethnic groups. Activities before and after school were valued, as were holiday playschemes.

Parents and carers wanted to see good quality facilities, with a wide range of activities for all age groups, at an affordable price with transport services to facilitate access.

INTRODUCTION

The Fostering Network

The Welsh Assembly Government commissioned the Fostering Network Wales to carry out a consultation with parents and carers in relation to the National Service Framework module on children in special circumstances. The Fostering Network is a membership based voluntary organisation with charitable status. Members are the adults concerned with children in care - foster carers, local foster care associations, local authorities and voluntary and independent organisations. The Fostering Network operates across the whole of the UK, with offices in London, Glasgow, Belfast and Cardiff.

The majority of foster carers in Wales are members of the Fostering Network. This means that the organisation was well placed to reach foster carers, who look after three quarters of the children and young people in Wales who are in public care. The organisation has fewer structured links with parents of children in public care but was, nevertheless, able to use a wide number of contacts to secure the attendance of parents. The meetings which were held are outlined below.

The Meetings

Five meetings were held across Wales. In order to maximise participation by different groups of parents and carers, they were held in urban and rural areas, in the north and in the south of Wales (including majority Welsh speaking areas) and at different times of day. They each lasted 3 or 4 hours, including breaks. Two of the meetings focussed particularly on foster carers and three focussed on parents (although, in practice, two of the meetings had a mixture of the two groups). In total, seventy-five parents and carers attended. The use of a wide variety of contacts to distribute invitations secured attendance by a diverse range of people, including parents and carers from a range of minority ethnic groups.

Their children included those with experience of:

- the care system or child protection system
- drug and alcohol problems
- the criminal justice system
- having run away
- being excluded from school or truanting
- being young carers
- living in very rural, isolated situations
- being part of travelling families
- living in families where there is domestic abuse
- being abused themselves
- abusing other children
- being young parents
- being part of a minority ethnic group
- using specialist education and health services (including mental health)

Methodology

The meetings were planned and facilitated by Anne Collis (freelance consultant) and Einir Tomos (Development Worker, Fostering Network Wales). They began with a short presentation to give participants some understanding of the work being undertaken in the development of a National Service Framework, to explain how the consultations fitted into this work and to clarify what would be done with the information gained from the consultation.

Structured exercises were then used to ensure that everybody had the opportunity to give their views without being obliged to speak in front of a large group of people. The first part of the consultation focussed on current services, inviting opinion as to the good and bad points in current provision. This part of the consultation used exercises such as 'opinion finders' - asking participants to agree or disagree with particular statements and to give their comments. More 'open ended' exercises were also used such as asking people to work in pairs moving around the room and writing on sheets their good and bad points about individual services.

In the latter part of each session, participants were asked to imagine that they were designing services from scratch. They gave their 'plans' as to what would be available and were given 'resources' to allocate to the different parts of the service. Throughout the sessions, any additional comments generated in discussion (through feedback from the exercises) were recorded. The consultation concentrated on health and social services but also included allied services, particularly education and leisure.

It should be noted that, because the methodology largely involved open questions and tasks, it might be that some issues of importance were not raised. However, all the issues raised were important to at least one participant. Both within and between meetings it was often possible to identify common themes. These are given in the executive summary above and expanded in more detail in the findings given below.

The feedback (given anonymously) from all participants showed that they had enjoyed the events, feeling that it had been 'worth coming' and that they had been 'listened to' by the facilitators. However, they expressed more scepticism as to whether their messages would be 'heard and acted on' by the Welsh Assembly Government.

The information below is organised by theme within particular services and illustrated by the direct comments of participants wherever possible.

HEALTH

Views on current services

There was a high value placed on the existence of universal health services, free at the point of use. This included access to General Practitioners (GPs), to dentists and opticians.

In general, participants felt that their GPs listened to them when they visited with an issue about their child and most felt that their GPs had sufficient time to do this.

'I never feel as though I am being rushed by my GP'

'very family friendly doctors'

Nevertheless, some people made the point that the service received depended very much on the individual qualities of the particular doctor,

'depending on which GP, some are very good, some no-one wants to see'.

One foster carer also felt that her doctor had,

'no patience' with her children, 'because they are in foster care'.

Health visitors were also generally valued, with several participants giving very positive comments about the service they received;

'My health visitor is brilliant'

'I think health visitors are very helpful'.

Although one participant felt that it,

'can be hard if your views are less conventional'.

As with GPs several comments were made that it depends very much on the individual professional,

'some get excellent health visitors, some get poor'.

Comments were also made about the apparent shortage of a variety of staff in the system.

'Not enough NHS dentists'

'Not enough medical staff'

'Not enough hospitals' and the need for 'more nurses'.

The shortage of mental health services was mentioned by many of the participants.

Securing convenient appointments was found by many participants to be problematic. Indeed, sometimes getting an appointment at all was difficult:

'you have to keep nagging to get an acknowledgement of the problem'.

Sometimes it was long waiting lists which caused problems:

'twenty one weeks for an eye test'.

Some participants commented that 'it depends on what service you need' and on 'how hard you push'. This theme of having to 'push', 'fight', 'complain louder' or 'nag' for services recurred throughout the meetings. Some participants highlighted the particular problems of certain groups of people in gaining access to services,

'children in temporary address in refuge have difficulty in accessing some services'.

Some participants felt that services were more quickly accessed by children in care, without them having to wait for too long. One of the groups which included both foster carers and parents had some debate about whether or not this was fair.

This issue of whether services were available equally to all arose in other comments, with participants expressing the view that it tends to depend where you live what service you receive and that some groups of people got better access to services than other. Typical comments included:

'articulate people get a better service'

'taken more seriously if professional than if a housewife'

'it depends on the area'

'rural areas have limited services'

'Merthyr is small so seems to get less'

Some participants also felt that cultural and language issues affected the service they received. They felt that there was a need for 'more interpreters in hospitals' and 'cultural awareness in health services' generally.

A lack of co-ordination between different parts of the health service causes problems for some parents and carers, from a clash in the time of appointments, to having to, 'repeat the same story over and over'. This experience was compounded where other services were also involved. These comments are just a few of those made along similar lines:

'communication needs to be more efficient'

'need for more multi-disciplinary and joint working'

'statutory services find it hard to work with voluntary organisations'

Lack of co-ordination was also raised as an issue when children moved area - continuity was seen to be important rather than 'having to start again', which had been the experience of more than one participant.

'Design-a-new-service'

When set the task of designing a new health service from scratch, the following themes emerged. Most groups believed that services should be very easily accessible, with more young people's clinics and 'drop-in' surgeries where appointments were not needed. One group suggested that computerised records should mean that anyone can drop into any clinic 'off the street' and medical staff would be able to access their records. Another group echoed these ideas in wanting a confidential service dedicated to young people, services where children would be seen straight away and which included counselling services. The need for counselling to be available to children and young people was raised by most groups.

One group gave the view that nursing staff should be trained to be able to do more of the 'basic jobs' to reduce the need to see a consultant. More treatment could then be given in the home and in the community, making treatment as informal as possible. One group raised the possibility of using video links to make more services available in rural areas.

Good information was also seen as a priority by the majority of participants, especially on 'drugs, drink and contraception' and 'healthy eating'. This information would need to be given in a format which was likely to be used by young people and in places they are likely to go - leaflets are not always the best way of doing this. Telephone help lines were seen as one way of making this information accessible to young people.

One group emphasised the need to give young people a voice in their services. The group wanted to see young people involved in local health boards and being given a choice of health worker and of therapies (including alternative therapies). Advocacy services were also seen as an important part of this involvement.

Most groups raised the need for more mental health services than exist in the current health service, with one group explicitly mentioning the need for more in-patient psychiatric care for young people.

Other priorities varied from group to group but included:

- the development of a well equipped children's hospital.
- all specialists 'under one roof'
- cleaner hospitals
- more resources to ensure a greater number of NHS dentists (and other staff)
- good working conditions for staff (especially pay and working hours)
- better education for children who are ill for long periods
- maternity services and ongoing support for teenage mothers
- free or subsidised transport to help with accessing services
- child-friendly surroundings where children can be treated in privacy and with dignity and where parents can stay comfortably
- more speech therapy, occupational therapy and play therapy
- more treatment for drug and alcohol problems
- two groups wanted to train young people to work with other young people on issues such as drug use or bereavement
- two groups wanted to charge people for wasting resources if they missed appointments

Several groups also indicated the kind of attitudes and values they would want to see permeating their new children's health services:

'child-centred workers'; 'child friendly staff', 'child friendly buildings', 'listen to young people', 'nice, friendly support staff', 'equality';

SOCIAL SERVICES

Views on current services

Individual participants acknowledged that Social Services were 'well intentioned' and 'tried to think what was best for the child'. One participant stated that the service 'saved children's lives'. One of the foster carer meetings outlined some individual services and systems which they thought were helpful:

- looked after children and foster carer review systems
- family support teams doing preventative work
- mentoring of foster carers
- computers provided for the use of children looked after
- fostering teams
- forums and support groups for foster carers

However, there were many more negative views expressed about social services; these views were often expressed strongly. In contrast to their view of medical professionals, most participants felt that social workers do not listen - to parents, foster carers or children and young people. One participant believed that it depends whether you are a foster carer or a birth parent whether or not you are listened to. Another participant raised the issue of potential conflict of views between parents or carers and their children and whose voice would be heard in such circumstances,

'What happens if parent and child disagrees?'

Services were described as, 'terrible', 'unhelpful', 'faceless', 'interfering and judgemental' with 'no common sense'. In all of the consultations people complained that Social Services were inconsistent. Social workers were described as inexperienced. There were several comments around the themes of paperwork and bureaucracy:

'Social workers work hard for the system but red tape stops them'.

Some participants expressed general criticisms about the system, 'the care system doesn't work' or that services had a 'bad impact on children and parents'. Some people felt that Social Services 'don't try hard enough to keep families together' or that they simply 'don't do what is required'. Participants felt that services needed to be 'more supportive of children and families', 'more aware of abusive situations' and spend 'more time with children and their families'. One participant expressed the view that staff should:

'Get off their high horse and live in the real world'.

There was a view from some participants that 'people from ethnic minorities get less services than mainstream clients'. This was coupled with criticism

that services were culturally inappropriate - particularly services delivered in the home.

Other criticisms of Social Services included:

- the stigma involved in using their services
- difficulty in contacting a duty officer
- lack of team working
- lack of training (specialist training and training for staff such as home carers)
- that they put too much pressure on foster carers

About a third of participants, when asked directly, did not feel that social workers treated parents with respect - although once again, the variation between individual workers was acknowledged. One participant felt respected but that this did not translate into the delivery of meaningful services:

‘They do respect parents but they don’t respond to their needs’.

Another, asked their opinion on the statement ‘social workers treat parents with respect’, responded:

‘you’re having a laugh!’

There was some acknowledgement of the difficult decisions involved and of the public scrutiny of much of what Social Services do:

‘Social services always get bad press- if they take a child out of the home they’re wrong. If they leave a child who is then injured, they’re also wrong’.

As with the health service, participants were aware of staff shortages and lack of resources. This was commented on both in respect of front line social workers and also management. The turnover of staff was also the subject of comment, with one person pointing out that it gave ‘no time to build a relationship’.

Information about Social Services wasn’t always readily available to participants - they found it difficult to know what was available and what they were entitled to. One participant felt that the service needed to ‘give more insight into why they are here’. Several participants commented that support was offered too late - it wasn’t until the family was in a state of crisis that any service became available.

'Design-a-new-service'

The groups dealt with a number of key issues. These included staffing, child protection, family support and the care system (including the foster care service). One group made the point that there should be a 24 hour a day service. The groups also wanted to deal with the public image and stigma associated with Social Services.

The new services designed by our groups of participants would have more staff and more resources. The emphasis for all our groups would be on 'fewer chiefs and more workers' with 'more frontline workers', more 'child care social workers', 'more foster carers' and more support workers and sessional workers of various kinds. One group said that there should be, 'equal amounts of ethnic minorities with adequate training and experience'. One person felt that children's need should be met 'by the best people for the job, regardless of language'.

Several groups mentioned the importance of staff being 'quality' and carers of a 'good standard'. Although one group believed that social workers should have 'practical life skills and more experience, not more qualifications'. Nevertheless, most groups mentioned that their staff and carers would receive training and that this should be accessible (including a crèche where needed to enable foster carers to attend). It was suggested that social worker training should include 'people skills'.

Social workers would have smaller caseloads and they would be given incentives to stay in their job rather than moving from authority to authority. They would do less paperwork. They would spend more time getting to know the children for whom they were responsible. All children would have a named social worker and that would be the same social worker from when they were first known to when they no longer needed a service, 'not changing social worker and team when the child's situation changes'.

The support available to social workers, foster carers, parents and children would be improved. There would be an 'independent body for social workers to take problems to'.

Child protection services would be more thorough, especially in making sure that concerns about neglect were properly dealt with. A team would be available to follow up these children through the schools and health services. Their needs would be assessed and 'processes put into being to meet these needs'.

There would be more effective and timely help to support children at home. This would include parenting classes, support for drug users, young offenders, and support for minority ethnic young people and their parents. Support services would be inclusive and accessible. One group recommended that this should be a different department - a 'department to help out parents who have difficulties with their own children'.

If children did come into care then they would each have a social worker who knows them well and could spend time with them, along with other workers to provide support and respite. People concerned with children looked after would all work closely together. The education and health of young people was acknowledged to be important. One group stated that they would ensure that the law was obeyed and all children in care were in school. One group felt that children would benefit from having a computer provided for their use in the foster home. Once children were in care 'problems at home (*would*) be dealt with before children return home', to avoid the home situation breaking down. One group felt that there should be 'less rights for parents and more for carers and children'.

A number of comments were made about the stigma faced by young people in the care system. 'Stop making children feel different if looked after.' One group particularly mentioned the need for schools to be sensitive in this respect.

One group raised the point that not all young people can live in families and that there should be 'more centres for children that are not fosterable or cannot live in families'. Another group raised the issue of the transition from care, saying that they would look at the situation of young people over the age of sixteen.

There were a number of ideas for improving foster care. These ideas included:

- 'sorting out consent issues relating to school trips, dentists,'
- 'sessional workers to take time with a child to give both the foster carer and child a break'; 'respite workers'
- 'independent supervising social workers - not part of the LA'
- 'a support service for foster carers with children who have behavioural problems'
- counselling
- 'someone to listen to the foster carer who has just coped with a difficult situation (on the phone if not in person)'
- 'more say for foster carers at a child's review'
- better financial rewards
- better information sharing
- better matching
- 'out of hours support - not just a phone line'

It was clear that most groups felt that the new Social Services would need to address an image problem. They would need to, 'make people want to trust Social Services' and do away with 'stigma and labelling'. General attitudes would include treating 'everyone as individuals and equally' and being open and accessible.

EDUCATION

Views on current services

As with health services, the fact that education is free at the point of provision was welcomed. Participants mentioned the opportunities to achieve given to children through education as a benefit and noted the importance of school as somewhere that helps children socialise. The facilities provided in some schools were mentioned positively. Some participants praised schools' efforts to be inclusive, 'some schools have listened and got better' (particularly in respect of black and minority ethnic issues and catering for different languages).

The provision of special needs teaching, help given to children in care including the development of personal education plans and positive attitudes towards children looked after and their families all came in for praise. The educational psychology service and educational social workers were also mentioned as helpful. The practical provision of taxis to enable children looked after to stay at their old school was also appreciated.

A number of specific initiatives in schools were commended:

- careers advice
- buddying systems for new pupils
- home tutors
- after-schools clubs
- Dragon sport

There were several positive comment about the attitudes and ways in which schools and their staff work. They were described as 'flexible' with 'parent/carer and school working together with clear guidelines'. One group felt that 'parents have an opportunity to make a difference' and one participant felt that teachers 'try'.

When asked specifically whether schools meet the needs of children, opinion was divided. On the whole, the majority of participants felt that they did. However, a number of comments were made about children's special needs remaining unidentified and being mistaken for 'laziness' or naughtiness. Once the special need was identified some participants found things improved, others continued to experience problems in getting all parties to agree on and implement an appropriate course of action.

There was strong agreement from the majority of participants with the statement, 'schools do not treat all children equally'. With participants commenting:

- 'treated differently depending on how they look and the clothes they wear'
- 'down to the individual teacher'
- 'either too many allowances made for children in care or not enough'
- 'depends on how they behave'.

Several participants mentioned the difficulties of securing services for children with special needs, which would give them equal access to education:

- 'not enough facilities or help for special needs'
- '3 year fight to get help for dyslexic child'
- 'lack of funding - now going backwards'
- 'the school is trying hard but the council says no money'
- 'have to keep pushing to get help'.

However, most participants felt that teachers are concerned for the welfare of children - although this varies very much depending on the individual teacher. Some participants felt that local schools were better and that 'primary schools are better in general than comprehensives'.

One participant raised the issue of child protection procedures acting to the detriment of children's welfare, with teachers not feeling able to give a hug to a child who is upset, feeling that they should not see children on their own, or should not give them a sweet. Others made the comment that large classes make it hard for teachers to care about the welfare of the individual.

'Design-a-new-service'

Although the 'design a service' exercise had been intended to look only at health and social services, one group specifically requested to work on education. This group wanted to see inclusive local schools providing a variety of types of education for different children, using a range of alternative educational learning models. Such schools would be available in all areas, including rural areas. Children starting school would learn through play rather than through formal lessons, their learning being led by the curiosity of the child. They would have lots of books and creative play resources. This style could lead into a vocational education which could be provided alongside the current secondary system. Special needs provision would be made within the school itself and this would mean that schools need to be wheelchair accessible. There would also be an increase in suitably qualified staff to facilitate this inclusive policy.

A broad and varied education would be provided. This would include vocational courses and the opportunity to work and learn outdoors. It would also include youth groups/Urdd running in the school and schemes outside of the school as an alternative to school. School nurses would be available to fulfil traditional roles and also to give family planning advice. School hours would be flexible to meet individual needs.

There would be no extra financial burden on families in this new school system. The school would provide gym kit and would also provide free school meals and orange juice.

LEISURE

Views on current services

Participants were very aware of the benefits of leisure activities to 'help to keep children fit and active' and to give confidence - 'everyone's good at something'. The issue of confidence-building was specifically raised in relation to 'disability sport'. Several other sports activities were mentioned positively, as were sports and leisure centres. There was also praise for friendly staff and for new developments. However, dirty, run down leisure centres were criticised, as were leisure centres without swimming pools.

There were other general criticisms about leisure services, with some people feeling that children with behavioural difficulties were excluded too easily, that some leisure centres didn't welcome young people and that leisure activities are 'behind the times'. One participant mentioned the difficulty of understanding how and when to access services, they 'need a guide to explain facilities, times etc.'. There were also some very specific criticisms raised such as the 'one child per adult rule at swimming pools' which caused problems.

Clubs of various kinds were mentioned as being good for children, especially those widely available such as youth clubs, guides and scouting. Youth clubs were felt to be well established and beneficial particularly in the 12-16 age group. Pre school, after school and holiday schemes were also appreciated, including activities aimed specifically at children looked after or fostering families (and respite or sessional work which helped young people access leisure). However, certain groups were felt to miss out, including particular age groups, with no schemes suitable for older young people. Some geographical areas also missed out with fewer opportunities to join in such activities (or, in some areas, long waiting list for things such as swimming classes). Youth clubs are not available everywhere and participants wanted to see more youth workers and more clubs.

Some minority ethnic groups miss out for cultural reasons as there aren't organised activities which meet their needs (such as girls-only groups). Children with special needs and homeless children were also mentioned as groups who cannot easily access leisure services. The timing of activities was also mentioned, with weekends felt to be a time when few organised activities are available. Some activities (such as youth clubs) stop during the school holidays and this creates a gap at a time when such services are particularly needed.

Participants felt that there is an overall lack of leisure facilities for young people age 16-18. They felt that this encouraged young people into venues such as pubs, clubs and discos, increasing the likelihood of them having

difficulties with alcohol and other drugs. Such venues were criticised for 'not monitoring age properly'. Other participants felt that there was also a lack at the younger end of the age range, with a lack of services for 5-7 year olds and under fives. One participant mentioned their worry that there is,

'no proof of police checking of leisure centre staff/children's club workers'.

Some participants raised the issue of the importance of providing what children themselves wanted - such as skate parks and also mentioned the benefits of involving children in developing facilities and activities.

The factor most mentioned by people taking part in the consultation meetings with relation to accessing leisure services was cost. This could be in a positive context such as the provision of free swimming (mentioned by every group), subsidised activities, or special schemes such as 'Passport to leisure', which were all very much appreciated. But it was also widely mentioned as a barrier to participation, with all of the meetings also raising cost as a negative issue.

'drawback is costs';

'can be expensive',

'cost is a major factor on what the child is able to enjoy'.

The meetings wanted to give the message that

'More help for low income families is needed'.

Transport was also an issue. Either public transport was not available at all (particularly in rural areas), or it was not available in the evenings when young people were using leisure services, or it was too expensive.

CONCLUSION

Participants gave a vast amount of feedback about what they liked and disliked in current service provision. They also made a great number of suggestions for the future. Highlighting some at the expense of others inevitably introduces an element of subjectivity. Therefore, only a few broad themes which emerged are mentioned here.

The participants in this consultation positively regarded universal services, free at the point of use; However, there were some barriers even to accessing universal services. These included homelessness, lack of provision in some geographical areas, or services which were not sensitive to the needs of minority ethnic groups or children with special needs.

Once services were more specialised, even though they remained free at the point of delivery, many participants felt that access was, at least partly, determined by who you are (including your class and the ethnic group to which you belong), how hard you 'push' for a service and whether the service is available in the area where you live. As children in special circumstances often need such specialist services, they are very dependent on someone to advocate on their behalf, on where they live and on whether they belong to a disadvantaged group. For services for which payment is made directly (most leisure services), then access is also determined by how much money you have.

In respect of all services, comments showed how crucial the individual worker is to users experience of that service. There were many very positive comments about workers and this usually meant that participants making these comments also had a positive regard for the service as a whole. However, the variability of the standard and attitude of workers in all services means that people using the service will always have a variable quality of experience. Social Services came in for particular criticism for having staff with poor attitudes, staff shortages, a high turn over of staff and a high number of relatively inexperienced staff, making it difficult to receive a quality service.

Bureaucracy and inconsistency were frequently criticised, as was a lack of communication and co-ordination both within and between services. However, a lack of resources, particularly of staff, was widely recognised. Some service gaps were identified, particularly mental health services and services relating to substance misuse. Some geographical areas lacked particular services.

The availability of good, accessible information was another theme. Parents and carers need to understand what services exist, how to access them on behalf of their children and what the criteria are for gaining a non-universal service. They also recognised that their children need this information directly, in a format appropriate to them.

In summary, participants wanted services in their local area, equally accessible to all. They wanted these services to be well resourced, with staff who would listen to them, respect them and involve them in decisions about the services their children received. They wanted accessible information about these services and for services to be consistent and well co-ordinated.