# INTEGRATING SERVICES FOR DISABLED CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES IN YORK: CONSULTATION PROJECT

**Commissioned by:**
City of York Children's Trust

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## Final Report

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# Chapter 1 Introduction

This report concerns the findings of a consultation involving professionals, parents and children and young people. Chapter 2 details the findings from the consultation on views about what needs to change in York with respect to ways of working, research evidence on these issues, possible solutions and ways forward suggested by parents and professionals, and our recommendations. Chapter 3 follows a similar pattern for the gaps in service provision in York identified through the consultation process. The final chapter provides a summary of the key issues emerging from the consultation and potential impacts of these issues on the five *Every Child Matters* outcomes for children, and highlights key recommendations. We begin, however, with a brief overview of the purpose of the consultation exercise and a description of how the work was carried out. This is followed by a summary of what the participants in the consultation have identified as good and valued services and ways of working in York. Finally in the introduction, we present the gaps and areas for change not taken forward in the second consultation because they were already being addressed in York or were beyond the scope of the consultation.

## 1.1 The purpose of the consultation

- To identify changes that can be made to improve outcomes for disabled children, young people and their families in York.
- To ensure that decisions made concerning changes to services are informed by consultation with all stakeholders and wider research evidence.

## 1.2 Overview of the consultation and methods

Parents, children and young people, and professionals were involved in the consultation. The consultation covered children aged 0-19 years. It concerned children and young people with a range of disabilities or long-term, complex health conditions, and included those with less severe disabilities. It was concerned both with children who attend special schools and those in mainstream schools.

The consultation sought stakeholders’ views on gaps in services and changes that need to be made to existing services or ways of working. These data were then supplemented by research evidence, collated by the consultation team, on ‘what works’ in better meeting the needs of disabled children and their families.

A range of methods was used to support the participation of all stakeholders, including focus groups, postal questionnaires and individual interviews.

The consultation exercise was overseen by a task group of managers representing Community Services, York LEA, York and Selby PCT and City of York Children's Trust Unit.

## 1.3 Methods

### 1.3.1 First consultation with service providers

A first wave of half-day workshops was held at the University of York in November 2004. Three workshops were held and were attended by 44 professionals (see Table 1).

**Table 1: Professionals who attended first wave of workshops**

| *Organisation* | *Number* |
|---|---|
| Children's Services | 10 |
| Community Services* | 3 |
| Connexions | 1 |
| Early Years/Portage | 4 |
| Education | 12 |
| Health | 8 |
| Leisure | 3 |
| Voluntary agency | 3 |
| *TOTAL* | *44* |

*Adaptations, Equipment, Housing

The workshops sought to identity participants' views on good practice in York, gaps in services and changes needed to services and/or service organisation.

For service providers unable to attend the workshop (n=39), a brief questionnaire based on workshop discussions was constructed and distributed (see Appendix A). Eight questionnaires were returned (see Table 2).

**Table 2: Professionals who returned questionnaires**

| *Organisation* | *Number* |
|---|---|
| Children's Services | 1 |
| Community Services* | 2 |
| Early Years/Portage | 1 |
| Education | 1 |
| Health | 2 |
| Sure Start | 1 |
| *TOTAL* | *8* |

* Adult Services, Disability Support (Community Occupational Therapists who also work with children)

### 1.3.2 First consultation with parents

A series of focus group meetings were arranged for parents in late November/early December 2005. Over 230 invitations to the meetings were distributed by the Family Fund, Sure Start and Portage. However, just seven families responded to the invitation. A single focus group was held for these parents, and five managed to attend. The group discussed services they valued for their child or themselves, things they wanted for their child/themselves and ideas as to how these things could be achieved. The team also consulted the group about ways to involve more parents in the consultation exercise. The group advised using a questionnaire.

In response to advice from the group a brief questionnaire for parents was constructed (see Appendix B). All special schools and mainstream schools with enhanced status within the City of York were approached with regard to distributing the questionnaire to parents of children with special needs. Both special schools, six mainstream schools, St Paul’s nursery and York College kindly agreed to distribute the questionnaire. Twenty-six questionnaires were returned (nine child in mainstream; 17 child in special school).

### 1.3.3 Consultation with children and young people

The consultation with children and young people was a single stage as opposed to two stage process. A range of different methods was used to find out about their lives at the moment and how they would want their lives to be. Children with a range of disabilities and with differing levels of severity participated in the consultation.

Young people with SEN statements attending York College and two mainstream secondary schools (n=200) received a brief questionnaire via school (see Appendix C). Nine questionnaires were returned. Nine pupils attending Applefields School and seven attending Hob Moor School also participated in the consultation. Individual sessions were held with the Applefields School pupils and a group session with the Hob Moor School pupils. A visual card-sorting exercise was used to facilitate the sessions.

### 1.3.4 Second consultation with service providers

A second phase of half-day workshops was held at the University of York in April 2005. Two workshops were held and were attended by 46 professionals (see Table 3).

### Table 3: Professionals who attended second wave of workshops

| *Organisation* | *Number* |
|---|---|
| Children's Services | 6 |
| Community Services* | 3 |
| Connexions | 1 |
| Early Years/Portage | 3 |
| Education | 16 |
| Health | 14 |
| Leisure | 2 |
| Voluntary Agency | 1 |
| *Total* | *46* |

* Housing, Adult Services (Transition), Adult Services (Learning Disability)

The workshops sought to explore how the identified problems in the way services were currently working, and the identified gaps in service provision, could be addressed in light of research evidence.

The areas for change in relation to ways of working and the gaps in provision discussed were:

**Ways of working**
- Multi-agency working
- Key workers
- Staff skills
- Workforce
- Child involvement
- Outreach/community based services

**Gaps in provision**
- Substitute care
- Information
- Family support
- Friends and leisure
- Transition
- Children's health & well-being
- Equipment and adaptations

Following a presentation of the research evidence on ways of addressing these issues, professionals were self-assigned to small groups to discuss specific topics (see Table 4).

### Table 4: Composition of small discussion groups

| *Topics discussed within group* | *Number of groups* | *Number of professionals involved* |
|---|---|---|
| Multi-agency working; key workers; outreach or community-based services | 4 | 33 |
| Staff skills; workforce; child involvement | 2 | 13 |
| Family support; substitute care; information; friends and leisure | 2 | 17 |
| Transition; health and well-being; equipment and adaptations; friends and leisure | 4 | 29 |

For each topic the groups were asked to draw up action points on what should be happening in the next six months and the next 12 months in York, and to note any current or forthcoming influences on, or barriers to, implementing a solution.

Following the workshops, a summary of the action points, influences and barriers was circulated to participants, for any additional feedback or to correct any errors.

### 1.3.5 Second consultation with parents

The second phase of the consultation with parents consisted of two focus group meetings. Parents who had responded to the invitation to attend the first round of focus group meetings (n=10), or who had indicated their desire to attend a parents meeting in the parents questionnaire (n=22), were invited to a daytime or an evening meeting. Six parents attended both the daytime and the evening meetings. They had children in a range of educational settings (see Table 5 below).

**Table 5: Educational settings for children of parents attending focus group meetings**

| *Education Setting* | *Number* |
|---|---|
| Pre-school | 1 |
| Hob Moor Oaks | 4 |
| Mainstream Primary Schools | 2 |
| Applefields | 4 |
| York College | 1 |
| *Total* | 12 |

The groups discussed the different options there might be for changing or improving services in relation to six themes where gaps or problems with services had already been identified. These were:

- Information
- Family support
- Substitute care
- Friends and leisure
- Transition
- Child and parent involvement.

For each theme a brief presentation was given on the key problems, and the possible solutions to them proposed by professionals in the second phase of workshops. Parents then discussed the solutions and suggested additional ways of addressing the difficulties.

With the exception of child and parent involvement, parents did not discuss possible solutions and ways forward to the problems with ways of working identified in the first phase of the consultation. This was because, with limited time available, it was considered more useful for parents to focus on the gaps in services they had highlighted as important rather than on organizational structures and cultures.

## 1.4 The nature of the evidence

A separate phase of this project has been to identify evidence which can be used to inform how York can move forward and respond to the findings from the consultation. A key feature of a lot of research on meeting the needs of disabled children and their families (both at the level of service organisation as well as service provision) is that evidence on 'what works' is very limited. There is a substantial body of research on families' needs and experiences as service users. Leading from this is research which has identified the factors or components which would appear to characterise 'good practice' in terms of meeting a need or addressing a service provision issue. However, there is very little evaluative research which has examined and compared different models of service delivery. This is the sort of research which would be able to tell us what works best in terms of meeting a need or how best to achieve a particular service configuration. In the following two chapters the findings from the consultation are presented alongside what the available research evidence tells us in terms of addressing that issue. As noted here, the type of available research does vary from issue to issue.

## 1.5 Valued services and ways of working

Professionals in York were generally optimistic about their services' abilities to achieve coordination of services, and it was felt that there was much that was good in the city in relation to the practice of and potential for multi-agency working. Both professionals and parents identified the Child Development Centre as an example of good multi-agency working. The fact that York is a small city meant that people from different agencies knew each other and this provided a good base on which to further develop multi-agency collaboration.

All participants in the consultations could identify good and valued services in York. The quality of short term care provided by the Glen and Sharing Care was highlighted by all stakeholders. It was recognised that these breaks provided a quality experience for young people themselves as well as time out for parents and other family members. Parents and professionals highlighted the practical support provided by Crossroads and also noted good social work support provided by the specialist Health and Disability team. Early Years provision, and the Portage service in particular, was highly regarded by parents and service providers for its pre-school support. A happy school life was a key priority for young people and their parents. Young people valued school and their teachers, and parents valued support to enable their children to take a full and active part in school. Staff highlighted good inclusive practices in mainstream schools which were supported by the Inclusion Support Service, Education Psychology Service, the Speech and Language Centre and CAMHS. Opportunities for young people to take part in play, leisure and sport activities and to meet others were also highly prized by young people and their parents. In relation to this, all stakeholders identified SNAPPY, PHAB and the PACT Student Scheme as high quality services.

## 1.6 Ways of working and gaps in provision not taken forward in the second consultation

Following discussion with the task group, not all the issues identified in the first phase of the consultation as areas for change in the ways services were organised and/or delivered or as gaps in service provision, were explored further in the consultation. This was because they were already being taken forward by the Trust, the Council or were being driven by national policy initiatives, or because they were simply beyond the scope of the second stage of the consultation.

### 1.6.1 Issues already being taken forward

Issues raised which were being taken forward elsewhere were early intervention, education, transport, and direct payments. These are described below.

### 1.6.2 Early intervention

The need for early intervention to prevent later problems was highlighted by service providers as a gap and an opportunity for services. It was felt that professionals should help families to look ahead and introduce them to services such as Shared Care so that relationships could develop before they needed to use the service or a crisis intervened. Another issue raised was that agencies should examine projections of future need to inform planning.

Early intervention was not taken forward in the second stage of the consultation because it was already being addressed by the Early Support Programme and in Children’s Trust planning as part of the preventative strategy.

### 1.6.3 Education

Service providers identified four distinct gaps and areas for change in relation to education. These were the need to ensure equal access on school trips; to provide specialist assessment of information and communication technology needs in school and at home; to equip and train staff in mainstream schools to meet the needs of children on joint school placements; and to improve wheelchair access in schools.

Seven parents who completed questionnaires referred to gaps and areas for change in relation to education, and education was raised several times in the focus group. Parents highlighted the need for appropriate support for their children in mainstream education. This ranged from help for their child when initially starting school, to ongoing support throughout their child's education. For one parent, the provision of information for parents was an important part of this process. For another, early and continued recognition of a child's special educational needs was important, 'it is only because of the statement that he is so successful'. Other parents wanted their children to feel included at school and not to feel 'exempt' from an activity or experience, such as sports education or school trips, because of their disability. Specialist support in school was also valued and some parents wanted to see a move away from the 'one size fits all approach'. Another parent wanted more therapists in school on a regular basis, not only to maximise their child's physical mobility but also to help get their child's additional needs recognised in school. Parents' suggestions for improving support in the mainstream included more staff training on special needs; more accessible school-based programmes with staff equipped and trained to manage these; and more teaching on a one-to-one or small group basis.

Another gap and area for change noted by parents, was the need to raise disability awareness generally in schools, since 'most prejudice comes from ignorance'. Suggestions for dealing with this were for 'more liaison with mainstream schools so children can learn from each other'; 'more education in schools about special needs'; and 'visits to special schools with mainstream kids'.

Finally, one parent identified the lack of a school for children with moderate learning difficulties as a gap in local service provision.

Education was not taken forward in the second stage of the consultation because it was already being addressed by York Institute for Citizenship in conjunction with York Children's Society in a consultation about school pupils' views on the inclusion strategy. Draft findings were presented in January 2005 to the Pupils/Parent Views Sub Group and Pupil Consultation Task Group.

### 1.6.4 Transport

Transport emerged as a strong theme at each of the provider workshops. It was seen as critical to supporting participation, inclusion and independence. Problems with transport mean that children are unable to attend after school activities, meet up with school friends or access sport/leisure facilities. It also means they are reliant on their parents to transport them around. Two gaps were identified in terms of public transport: accessibility of the vehicles and supporting children/young people to learn how to use public transport.

At the workshops, however, the discussion tended to focus more on the school transport service. The inflexible nature of the current service meant that children were unable to stay on for after school clubs, or could not easily change the day they attended after school provision such as SNAPPY. In addition it did not provide transport to work placements. Participants believed that the school transport service provided in North Yorkshire was more flexible and might provide ideas about how to change/restructure the service.

In addition to making changes to the school transport service, the need to provide training on using public transport was suggested, with this training beginning from an early age (see YILTS initiative below).

*Young people's views*
Getting to places was seen as a key barrier to doing things. As one young person said: 'It's the 'getting to' that's the problem'. They sometimes knew about things that were going on but had no means of getting there. Some families did not have a car which greatly limited out of school activities. Some wanted to be able to use public transport by themselves or with help from a non-family member. One young man wanted someone to help him learn routes so he could cycle to places he wanted to get to, such as the local sports centre.

Transport was not taken forward directly in the second stage of the consultation because it was already being addressed by:

- York Independent Living Travel Skills Initiative (YILTS) which was set up in November 2004 and is running to July 2005. Its aim is to get young people (Yr 11) out of taxis and on to public transport. There is a YILTS coordinator who develops an independent travel plan for a young person and then works with the young person to develop the necessary skills.
- The National Institute of Adult Continuing Education which is carrying out a review of transport in York.

However, transport issues relating to children and young people's access to leisure opportunities were discussed in the second stage consultation (see Section 3.4).

### 1.6.5 Direct Payments

The issue of Direct Payments was something that the Children’s Trust had flagged up of being of interest to them. However, given its very low-take up (and low profile) among families with a disabled child both locally and nationally it was unlikely that the consultation with parents would generate much comment on this particular way of supporting disabled children and their families. This was indeed the case with just one parent offering cautious approval of Direct Payments while mindful of the extra burden it could place on parents.

Direct Payments were, however, raised by participants at two of the three provider workshops. The belief was that Direct Payments need to be promoted more in York, and the scheme extended to young people aged 16-17 years.

This issue was not taken forward in the second stage of the consultation because it was already being addressed by the Children’s Society in York which is currently conducting a piece of work on Direct Payments.

## 1.7 Issues beyond the scope of the second stage of the consultation

Issues raised which were beyond the scope of the second stage of the consultation were funding, monitoring and evaluation, parking and access. The problems identified with these issues are described below. These issues were noted by the task group and will inform discussions in the Trust, but it was not felt that further consultation was needed on ways to address them.

### 1.7.1 Funding

Problems of lack of funding for essential services and insecurity of funding for valued services were identified by service providers and by the parent focus group and four parents completing questionnaires. Staff noted that it was easier to get money for new projects than to keep good projects going in the long term. They felt that good projects that had been funded on a short-term basis should become part of core services with secure funding rather than be constantly under threat. A number of examples of services that were not funded or were vulnerable were given, including Homestart Resource Centre, lack of funding for crèche workers, cessation of CYC funding for Mencap and Pathways, and the need for more certainty about funding for SNAPPY. Parents valued SNAPPY greatly but were concerned about its funding – 'SNAPPY is brilliant but it seems constantly under threat which is worrying for all of us'. They felt that children's services should be a higher priority for CYC funding and in particular that services for disabled children appeared to be 'easy targets for saving money regardless of the consequences'. Staff also noted effects of financial restrictions and increasing pressures with budget cuts. Parents wanted funding for extending early years services, such as Portage beyond the early years and highlighted the need for securely funded social and leisure services for teenagers that continue all year, not just in school term time.

### 1.7.2 Monitoring and evaluation

Staff and one parent noted the need for services to monitor their provision. Staff felt that professionals should be open to peer evaluation of performance and outcomes of services. The parent felt that local services should be reviewed for the service they provide for disabled children and their families, as it often seemed as if families had been forgotten when they contacted services to find out if something was happening.

### 1.7.3 Parking

Parents identified three problems with parking. First, the inadequate number of disabled parking facilities across the city. This applied to parking for shopping and other leisure activities, attending hospital appointments and outside schools and nurseries. Second, the need for designated parking spaces outside their homes was raised. Third, the eligibility criterion for the Blue Badge scheme currently excluded some families. Two parents explained that, while their child was not physically impaired, taking their child out and about was extremely difficult because of their behaviour and supervision needs. Being able to park as close as possible to their destination would make life easier for them.

### 1.7.4 Access

Providers noted that difficulties with accessing public buildings presented problems to some families. A council-wide access standard (above national building regulations) was suggested at one of the workshops. In addition, participants at one workshop noted that there needed to be more accessible toilets in York.

# Chapter 2 Ways of Working

## 2.1 Coordination and multi-agency working

### 2.1.1 Gaps and areas for change

Coordination and multi-agency working was a key theme in service providers' discussions. The gaps identified were:

- Staff felt they needed a clearer understanding of the interfaces between different agencies and departments, and opportunities for sharing information and gaining knowledge of roles and responsibilities of each agency, so that different professionals are aware of services provided by others and what those services offer, understand the constraints under which different agencies operate, and build up contacts in other agencies.
- There was a need for a common language and core principles for service provision.
- Coordinated assessment was needed with joint working around assessment and history taking.
- Coordination between health and education was specifically identified as requiring improvement, particularly for children in mainstream schools.
- A fully coordinated approach was felt to be needed for young people at transition to adult services, both between children's and adult services and within the different agencies providing adult services. This appeared to be a problem for all services. Young people with autistic spectrum conditions (ASC), physical disabilities and mild or moderate learning disabilities were experienced as having no coordinated adult services and links between adult services and CAMHS were also mentioned as problematic.
- More liaison with leisure services and closer working with the voluntary sector was also thought to be needed.

Staff identified a number of solutions to these problems at both strategic and operational levels. It was felt that there should be more coordinated planning around the whole range of need, joint commissioning and funding of services such as equipment and continuing care, development of systems which allow information sharing between agencies and clarification for all agencies of confidentiality rules around information sharing. Creation of multi-agency teams focusing on front-line service delivery and co-location of professionals working with children and families were both seen as ways of stimulating joint working. It was felt that a central base for all professionals caring for disabled children to meet and network could be useful and the potential of Integrated Children's Centres as means of bringing people together and providing 'one stop shops' for families was noted. Finally, staff noted the need for a coordinated appointment system for the three statutory agencies centred around the child and parents' needs not those of services.

Parents had less to say that was directly about coordination but the focus group noted the need for more joint working between health and schools. They felt that some schools and nurseries were not equipped to cope with health care and so the onus was on the parent to provide this support to their child in school. This could make it impossible for parents to go out to work.

### 2.1.2 Research evidence

There has been a considerable amount of research on processes of multi-agency working but much less research exploring outcomes for service users, and so there is no strong evidence on models of multi-agency working that provide the best outcomes for children and families. However, there is good agreement between different studies and reviews of research on factors that facilitate or act as barriers in the planning, implementation and ongoing management of multi-agency services (Linck *et al*., 2001, 2002; Cameron and Lart, 2003; Sloper, 2004). In planning the service, studies suggest that successful multi-agency working is promoted by:

- Clear and realistic aims and objectives which are understood and accepted by all agencies.
- Clearly defined roles and responsibilities, so everyone knows what is expected of them and of others, and clear lines of responsibility.
- Commitment of both senior and frontline staff, which is aided by involvement of frontline staff in development of policies.
- Strong leadership and a multi-agency steering or management group.
- An agreed timetable for implementation of changes and an incremental approach to change.
- Linking projects into other planning and decision making processes.
- Ensuring good systems of communication at all levels, with information sharing and adequate IT systems.

According to research studies, the implementation and ongoing management of multi-agency services requires:

- Shared and adequate resources, including administrative support and protected time to undertake joint working activities.
- Recruitment of staff with the right experience, knowledge and approach. Interestingly, Atkinson *et al*. (2002) in a study of multi-agency working that involved education, found that many of those involved in the multi-agency initiatives had worked in multiple agencies during their career, suggesting that a new type of 'hybrid' professional may facilitate joint working.

- Joint training and team building. Multi-agency coordination requires different ways of working, greater understanding of the roles of other agencies and professionals and respect for these roles. Provision of training for this is crucial.
- Monitoring and evaluation of the service, with policies and procedures being reviewed regularly in the light of changing circumstances and new knowledge.

A past history of joint working between the agencies involved allows agencies to build on previous arrangements; and co-location, in shared offices or the same building, increases opportunities for communication between staff, promoting understanding and information sharing.

Many of the barriers to development of multi-agency working are the lack of or opposites of these facilitators, for example, lack of clarity regarding roles and responsibilities; differences in organisational aims, lack of consensus on aims or overambitious aims; lack of commitment and support from senior management; inadequate resources and lack of joint budgets; lack of ongoing training; lack of leadership; lack of time for joint working.

In addition, other factors found to inhibit joint working are:

- Constant reorganisation
- Frequent staff turnover
- Lack of qualified staff
- Financial uncertainty and difficulties in ensuring equity from partner agencies.

### 2.1.3 Views on how to move forward

As noted above, staff had already identified some solutions to the gaps in joint working in York in the first consultation meetings. At the second meetings, they went on to consider these and the research evidence, and outline some priorities for action. There was a clear will to work together more effectively, staff supported the move towards multi agency working and integrated services and noted that this would ultimately require shared budgets, joint appointments and integrated teams. It would also require the inclusion agenda to permeate all levels of multi-agency working from the strategic planning of services, such as transition services, to their frontline delivery.

Staff saw co-location as part of the ultimate solution to multi-agency working:

> The ideal would be to have a Children's Centre where professionals across the boundaries rubbed shoulders, shared training and worked together regularly. Putting people in the same building does work. It takes away the mystery and gets people sharing ideas at all levels.

It was suggested that an integrated IT system across and between services would enhance multi-agency working, but that this would require commitment at a strategic level.  There is also a need to take forward information sharing protocols and systems and to have a shared and agreed definition of disability.

Staff agreed that multi-agency working would be strengthened by producing a directory of local services for professionals that clarified the roles and responsibilities of different agencies and departments working with disabled children and their families.  They felt a web-based directory would be preferable since it could be updated frequently.

A number of opportunities that could be built upon in York were identified.  It was suggested that multi-agency working practices instigated as part of the Early Support Programme in York could be used as a template for multi-agency working beyond early years.  Staff also suggested building on the existing multi-agency groups such as the Autism Spectrum Disorder Forum, the Learning Disability Forum, the Joint Agency Panel, and the Children's Joint Management Group.  However, staff wanted a clear lead on multi-agency working, and a named person responsible for driving this forward.

It was widely felt by staff that multi-agency training would promote multi-agency working by helping to foster a better understanding of different professional roles and to facilitate information sharing between professionals.  This training should include disability awareness training so that staff were better equipped to meet the needs of children and young people with a wide range of disabilities.

A clear need was identified for professionals from different agencies such as social services, education, health and the voluntary sector, to get to know each other and learn about each other's roles.  Staff who attended the consultation groups had found these very valuable as a forum to meet and discuss services with colleagues from other agencies and suggested that another joint event, such as a launch event (possibly for the re-branding of *YorOK*) where the findings of the various recent consultations on services for disabled children could be shared, would help to build on the consultation process.

There was also a suggestion from staff that a cultural change is needed for multi-agency working in York to succeed.  As one professional noted:

> Multi-agency working tends to be the first thing managers cut when finances are tight, because they don't see these roles as 'core' work.  We need to change the culture so that multi-agency working is core and isolationism is not.  We need to have funding mechanisms that protect integration and don't mitigate against it.

Staff noted that multi-agency working takes time to develop, particularly in the early stages, and it is important that this is reflected in people's workloads.

### 2.1.4 Recommendations

- The consultation identified a clear opportunity to build on the evident enthusiasm of staff for developing multi-agency working and on the impetus developed in this consultation by holding an event for staff providing services for disabled children to meet together. This event could present findings from various recent consultations on this topic and identify how the Trust intends to take these forward.

  There are a number of developments in multi-agency working in York which address some of the gaps identified in the consultation. These include developments regarding integrated IT systems and information sharing protocols which are being taken forward as part of York's preventative strategy; discussions about Integrated Children's Centres and whether one can be located with a special school; and discussions around how common assessment can be applied in the preventative strategy. Holding an information sharing event for staff working with disabled children would enable all staff to hear about these developments.

- The development of Integrated Children's Centres can provide an opportunity to work towards an Intergrated Children's Centre base where some staff can be co-located and which can act as a base and meeting place for all staff providing services for disabled children.

- Identifying a leader (a 'champion') who will take forward plans for integrated services for disabled children would help to ensure that the needs of disabled children and their families are an important part of the broader agenda for multi-agency working.

- Other recommendations from the consultation that will help to ensure that services for disabled children become better integrated are:
  - Instituting joint training (for example, on roles of all agencies and professions, disability awareness) and producing a web-based directory of local services that clarifies roles of all agencies and includes contact details for staff.
  - Ensuring recognition at all levels of management of the time commitments engendered by developing multi-agency working, and consideration of how the implications for staff caseloads can be managed, particularly in the early stages of integrating services.

## 2.2 A key worker service

### 2.2.1 Gaps and areas for change

Provision of a key worker service was identified as a gap, and a solution to some of the problems arising from lack of coordination, by both service providers and the parent focus group and one of the parents completing a questionnaire. Staff felt that the Early Support Programme (ESP) model should be extended across all age groups and noted the importance of a clearly defined and proactive key worker role. However, it should be noted that the ESP key worker system is only in the initial stages of implementation so it will be important to monitor and review this before extending it.

### 2.2.2 Research evidence

Research on the experiences of families with disabled children continued throughout the 1980s and 1990s to find that one of the most common causes of problems for families was lack of coordination of services and lack of key workers. Many studies over this period found that less than a third of families with severely disabled children had a key worker (for example, Quine and Pahl, 1989; Sloper and Turner, 1992; Beresford, 1995; Chamba *et al*., 1999). Even when families did have someone they saw as a key worker, this tended to be on an *ad hoc* basis, at the initiative of an individual professional, and if this professional left the service, the role did not continue. Key working was rarely part of the system. A national survey of Child Development Teams (McConachie *et al*., 1999) confirmed this picture. About half did not have a coordinated assessment process and only 30 per cent reported that a key worker would be allocated to a family. Where no system of multi-agency coordination is in place, professionals themselves struggle to coordinate services without multi-agency backing and commitment (Mukherjee *et al*., 1999).

There is a fairly small body of research in the UK and the USA that has looked at the effects of having a key worker (for example, Glendinning, 1986; Marcenko and Smith, 1992; Sloper and Turner, 1992; Beresford, 1995; Koren *et al*., 1997; Prestler, 1998; Mukherjee *et al*., 1999; Tait and Dejnega, 2000). Some studies have simply compared families who say they have a key worker with those who do not, so attributing differences to key workers in any individual study is problematic. Others have been small scale qualitative evaluations of a local service. However, consistency of findings between studies adds weight to the evidence. Liabo *et al*. (2001) reviewed the evidence and concluded that findings indicate that:

- If they receive a key worker service, the overall quality of life for families is improved.

- Specific outcomes are better relationships with services, better and quicker access to services and benefits, and reduced levels of stress.
- Good personal relationships between key workers and parents are reported by parents as important factors and of value in themselves.
- Key workers report satisfaction with the role and believe that it makes a positive difference to the lives of children and families.
- While a key worker in the role of independent advocate can be effective, a key worker who works for a service appears more able to access resources necessary to meet families' needs.

Evaluations of key worker services have also identified the key activities of the role (Glendinning, 1986; Mukherjee *et al*., 1999; Tait and Dejnega, 2000). Both key workers and families reported that the role of the key worker encompasses:

- Providing information and advice to the family
- Identifying and addressing needs
- Accessing and coordinating services for the family and ensuring their timely delivery
- Providing emotional support
- Acting as an advocate for the family.

The balance between these activities will differ for different families and at different times in a family's life. This underlines the importance of the service being flexible and responsive to families' views and needs.

Families reported that the following elements were important in a quality key worker service (Glendinning, 1986; Mukherjee *et al*., 1999):

- Proactive, regular contact initiated by the key worker.
- Listening to families and developing a supportive open relationship, promoting a sense of trust which allowed family members to be honest and open with their key worker.
- A family centred approach, acknowledging and exploring the needs of all family members, not just the disabled child.
- Working across agencies, including health, education and social services, but also others, such as housing and the Benefits Agency.
- A flexible approach, identifying families' strengths and preferred ways of coping, and negotiating with them as to the support and input needed from the key worker and other services. The negotiating model for working with families (Dale, 1996) seems to be central to a good key worker service.
- Working for the family rather than working solely within a certain professional or agency role. If necessary, some families wanted key workers to be able to act as advocates for them or point them to advocates.

The picture obtained from a UK-wide survey of care coordination and key worker services, carried out in 2002 (Greco and Sloper, 2004), was one of considerable diversity.  Only 30 areas were identified as providing key worker services.  There was much emerging that can be recognized as good practice.  The majority of the care co-ordination schemes had all three statutory agencies involved in setting up and overseeing the scheme, indicating a substantial commitment to promote and support multi-agency working.  In most cases, parents were involved in setting up and overseeing the schemes.  Other encouraging results were that many schemes had open referral, enabling parents and families to refer themselves and their children to services, and that most of the schemes covered all age groups of children.

However, other aspects that have been suggested as good practice were less common.  Although agencies were jointly setting up and overseeing the schemes, joint funding from all three statutory agencies was still rare.  In addition, short-term funding for many of the schemes was a concern.  Few schemes were using the opportunity to pool budgets provided by section 31 of the Health Act 1999.  The extent of training received by the key workers varied greatly across the sites, and some of the schemes provided no training.  The likely consequences of a lack of training are that key workers will not understand their new professional role and will not be able to provide families with the type of support they are expected to offer (Mukherjee *et al*., 2000).  Arrangements for supervision of key workers were also variable.  Nine schemes had no initial planning meeting held between the family and the professionals involved in care.  Such planning and cooperation is seen as essential in order to avoid duplication and omission of support to children and families and as an important condition for care coordination and multi-agency working (Healey, 1989; Yerbury, 1997).

Two recent studies (Townsley *et al*., 2004; Greco *et al*., in press) have looked at different models of care coordination and key worker services and started to identify the characteristics of services that provide the best outcomes for families.  Both studies found considerable variability in families' experiences both within and between services.  A key finding was a lack of clarity about the role of the key worker in some services.  This confusion applied not only to parents who received the service but to key workers themselves, and services where there was such confusion showed poorer outcomes for families.  The characteristics of services found to relate to better outcomes for families were:

- Regular training, supervision and support for key workers in their key worker role.
- A multi-agency steering group, involving senior managers from each agency, who have the power to commit resources, and parents.
- Some dedicated funding for the service.
- A service manager.
- A clear job description for key workers.

- Multi-agency care planning and review meetings, with key workers supporting families to prepare for and take part in these meetings.
- Key workers carrying out the different aspects of the role including: providing information and advice about services, emotional support, identifying and addressing needs of all family members, coordinating care, improving access to services, support in a crisis.
- Appropriate levels of contact between key workers and families.

### 2.2.3 Views on how to move forward

Staff wanted explicit agreement between and within agencies on the model of key worker service to be used in the city, multi-agency support for the development of a key worker system, and a shared definition of, and clear guidance on, the role of key workers, including detailed job descriptions. It was noted by staff that a key worker service would benefit from many of the suggestions already put forward under multi-agency working, such as multi-agency training, a directory of services and a forum for key workers to share information and network, and that training and skills for key workers were crucial.

Staff highlighted the role of the three ESP key worker coordinators in developing systems and protocols in conjunction with the ESP implementation group. They felt that systems and protocols for extension of the service should take account of the early key worker experiences from the ESP. They felt that the role of all agencies within the key worker service should be clear and coordinators should liaise with services to establish a ‘menu’ of those willing to act as key workers, and protocols should address how families identify key workers from this ‘menu’ of workers. It was suggested that the extended service should build on ESP services and training, and that there should be awareness raising and training for all staff on the role of key workers. It was felt that the success of a key worker service was predicated on developing good multi-agency working and knowledge and awareness for all staff.

It was noted by staff that since key workers can change, regular reviews and assessments need to be built into the service, so as to clarify who is taking the lead for a particular family at any given time. They suggested preparing a flowchart review plan which takes account of the views of parents and, especially as the child grows older, of the child.

It was suggested that finding protected time for non-designated key workers to undertake the role could be problematic. Staff were mindful that a key worker service would need careful monitoring to avoid overloading individual workers, that there should be effective caseload management for staff acting as key workers, and suggested that all requests for key workers are routed through managers. They also noted the importance of key workers having ‘power’ and agencies and professionals supporting and signing up to the system.

### 2.2.4 Recommendations

The implementation of ESP provides a good opportunity to develop and monitor the impact of a model of key working for York.  The consultation clearly supported the extension of a key worker service to a wider age range of children.  There is also enough evidence on the benefits of key workers for families to support the view that the service should be extended and considerable evidence is now emerging on the important characteristics of an effective service.  It is recommended that a multi-agency group takes this agenda forward, drawing on lessons from the development of the ESP service and the research findings detailed above on characteristics of effective key worker services to inform the model of service for York.

## 2.3 Staff skills

### 2.3.1 Gaps and areas for change

Service providers, the parent focus group and nine parents completing questionnaires felt that disability awareness and training for staff in mainstream services was needed.  Hospital provision for children with autistic spectrum conditions or learning disabilities was noted as problematic.  Staff felt that a specially trained nurse was needed and parents thought that hospital nursing staff needed training in working with disabled children, particularly those with ASC or LD, and their families.  For example, the agitation and distress experienced by children with ASC when they have to wait for appointments and so on, was little understood.  Similarly, service providers felt that staff in mainstream schools, including those involved in joint placements with special schools, were not properly trained and prepared to meet disabled children's needs, and that training for teachers in speech, language and communication was poor.  One parent highlighted lack of training around ASC for school staff as a particular problem.  Other groups identified as needing disability awareness training were nursery nurses, leisure, library staff and bus staff.

In order to address some of the issues of multi-agency working, staff wanted more opportunities for training in a multi-agency environment.

One parent felt that staff, parents with disabled children and parents of mainstream children should have training in the Person Centred Planning so that the scheme would gain momentum.

> The recent inclusion strategies in education would be a perfect opportunity for Person Centred Planning to really take off. In the long term if people with disabilities could access their needs and desires through their own network of appropriate support, the need for formalised care would be reduced. Children, families, young people would feel empowered and less segregated.

An issue raised by the parent focus group, but not by service providers, was the need for some staff to have better listening skills and 'more open minds ... a dynamic approach'.

### 2.3.2 Research evidence

There is, as yet, little evidence on the effects for children and families of disability awareness training for staff. However, it should be noted that this does not mean that there are no positive effects, simply that the research has not been done.

One of the potential ways of improving multi-agency and multi-disciplinary working is joint rather than separate education of different professional groups. However it is not clear whether this has any wider effects on practice or on outcomes for families. A systematic review of interprofessional education (IPE) compared with separate education found that studies lacked methodological rigour and therefore no conclusions could be drawn as to whether IPE does in fact have any positive impacts on professional practice and/or care outcomes (Zwarenstein *et al*., 2002). A parallel review (Koppel *et al*., 2001) extended the focus to include a broader range of outcomes and study methods, including qualitative studies, and addressed the question: ‘What kind of IPE under what circumstances produces what kind of outcomes?’ Tentative conclusions from the examination of factors affecting outcomes were that ‘IPE may be more effective at improving patient care or changing the organization of care if it is of longer duration, delivered in the workplace'. IPE also seemed to be more effective in delivering these outcomes when carried out at the level of continuing professional education, rather than as part of undergraduate or postgraduate education. However, undergraduate and postgraduate education did show effects on students’ reactions and learning.

In the consultation, some parents identified problems in communication with professionals. Research shows that both children and parents report difficulties in communication: professionals not having enough time; presence of students or other people and lack of privacy; lack of continuity of staff; use of jargon and complex language; receiving conflicting information; insensitivity to their needs and failure to address emotional and psychosocial issues (for example, Beresford, 1995; Bradford, 1997; Beresford and Sloper, 2003). In addition, children and young people report that professionals often exclude them from the conversation by focusing their attention on parents. These difficulties stem in part from the organisation of services and in part from deficits in professional communication skills. A systematic review of interventions which include training for professionals in patient-centred approaches concludes that there is fairly strong evidence that such training increases the patient-centredness of care and some evidence that there is a positive impact on patient satisfaction, but evidence on effects patient health behaviours is mixed (Lewin *et al*., 2002). This review includes two studies on the effects of brief communication training for professionals working in paediatric settings (Clark *et al*., 1998; Lewis *et al*., 1991). These showed positive effects. Post-training effects include:

- Professionals providing clearer information and more often including children in the discussion.
- Parents having more positive views of the professional.
- Children recalling a higher percentage of recommendations and being more satisfied.
- Better parental management of the child's condition.

However, these studies do not look at training to meet the special needs of disabled children. Specialist training in communication with children who use communication aids will also be required.

### 2.3.3 Views on how to move forward

Service providers felt that multi agency training, supported by lead officers within each agency, would improve staff skills as well as foster a better understanding of each other's roles. It was suggested that the Children's Trust should co-ordinate multi-agency training and drive this forward.

It was suggested that there should be multi agency training on:

- Disability awareness
- Communication skills
- The roles of different agencies.

Staff suggested involving parents in training sessions, and also wanted training sessions to be evaluated, particularly in terms of multi-agency attendance.

It was noted that there are already a number of developments driving a joint training agenda in York, including the Children's Trust, Shared Foundation Community Partnerships around schools, development of Integrated Children's Centres and extended schools, and multi-agency child protection training. These were seen as providing good opportunities to drive forward this issue.

### 2.3.4 Recommendations

As noted in section 2.1, staff felt that joint training was important in promoting multi-agency working. Staff taking part clearly saw a need for joint training on the issues identified above and it is recommended that discussions in York around the government's Workforce Strategy and its implications for training should include consideration of these issues and develop a plan to institute a programme of joint training.

## 2.4 Workforce

### 2.4.1 Gaps and areas for change

Workforce issues were mainly raised by service providers. These concerned lack of carers and befrienders and trained leisure staff to provide leisure opportunities for disabled children; and insufficient numbers of therapists (occupational, speech and language and physiotherapists) resulting in long waits for treatment, and assessment for adaptations and equipment. It was felt that more specialist staff were needed, including therapists, outreach mental health workers and Connexions workers.

### 2.4.2 Research evidence

It is important to note that the issues identified around shortage of specialist staff are a national problem and one that is unlikely to be resolved in the short term. There have been a number of responses to this situation, key ones being:

- The use of therapy assistants.
- The development of new ways of working, such as the blurring of boundaries between the roles of different therapists.
- Cascading skills to parents.

There has been a considerable increase in the use of therapy assistants over the past 20 years, for example 20 per cent of physiotherapy workforce is now physiotherapy assistants. At the moment assistants are most often found working in community based work and work with older people. Key issues that have emerged in the use of assistants are (Ellis *et al*., 1998, 2001; Department of Health/Department for Education and Employment, 2000; Clarke *et al*., 2001):

- The need for a more standardised approach to the role of therapy assistants.
- The need for improvements in training.
- The need to develop systems by which it is possible to identify children who need a therapist and those where an assistant is sufficient.

These require development at a national level and further research, although local services could address training and supervision needs.

Blurring of boundaries between therapies refers to therapists doing work that is traditionally done by another therapeutic group. Again, this is a relatively new venture and there is no evidence on its effectiveness or not. There is, however, evidence on what supports this (Read *et al*., 2001):

- Training, with some indication that inter-professional training is the most effective route.
- Interprofessional, strategic planning of the workforce.
- Organisational change to allow cross-over of people and information between different departments and agencies, for example, housing departments accepting the assessment of OTs working in social services departments with regard to housing need.

Cascading skills to parents is not a new development. Teaching parents skills with regard to the care and development of their child, nursing care, and educational interventions has been established in practice for many years, for example, in services such as Portage. In terms of therapeutic input, research has shown that (Mayo, 1981; Hanna and Rodger, 2002):

- Parents can be effective therapists.
- BUT they need appropriate/sufficient levels of support from therapists.
- There is some evidence that home visits are the most effective way of providing that support.

We also know from research that parents view parent-led therapy at home as very important, but it is very difficult to juggle with other priorities. Parents feel that therapists don’t take enough account of the need to integrate therapeutic regimes into everyday life (Parkes *et al*., 2002).

There is little research evidence on effective ways of addressing the lack of carers, befrienders and trained leisure staff to provide disabled children with access to leisure opportunities. National evidence (Finch *et al*., 2001) also points to lack of trained staff and carers as factors in the considerable problems identified in disabled children's access to sport and leisure opportunities.

### 2.4.3 Views on how to move forward

Staff felt that the critical shortage of workers identified earlier in the consultation could only be addressed by more funding and that this was necessary if York was to meet its obligations under the Children’s National Service Framework. As one professional noted:

> Having psychologists in child development centres and in clinics (for example, for epilepsy) would just not be possible without more funding. There used to be a children's social worker with a room on the children’s ward, and a paediatric liaison health visitor used to come to the paediatric psychosocial meeting every week. These things have both gone.

Whilst skill mixing was acknowledged as one of the ways of dealing with shortage of staff such as therapists, it was felt that skill mixing was already happening and that there were limitations to this for addressing the shortage of specialist staff. However, ‘more creative use of pooled budgets’ was suggested to facilitate joint working.

### 2.4.4 Recommendations

- Many of the issues about workforce have to be addressed at a national level. It was interesting that staff in York felt that skill mixing was already happening here and that other ways of addressing shortages were also needed. It would be useful to review the use of therapy assistants in the city to get a clearer idea of what the position is and whether there is room or need for improvement, for example in training. The role of the Children's Trust could be helpful in facilitating strategic planning on the workforce across agencies and promoting cross-over of people and information.

- Cascading skills to parents has a long history and is welcomed by parents as long as the need to fit interventions for the disabled child in with other demands of family life is recognised. Joint training for professionals should also focus on models of partnership working with parents (see below).

## 2.5 Parents' involvement and young people’s involvement

### 2.5.1 Gaps and areas for change

Parents and service providers both highlighted the need for more parent involvement in services, but had somewhat different perspectives on this. Service providers felt that there should be more recognition of parents' and children's expertise in their own assessment and that parent held files should support choice making about sharing information and how the child's history is conveyed. Parents themselves wanted 'a real say', 'a direct voice’, and 'more power'. One parent noted that parents should have the chance to be 'a serious part of planning processes' and not just via consultation exercises.

The experiences of young people who had taken part in meetings about themselves were mixed. The sorts of problems they talked about included finding the meetings boring, missing out on school, not being sure about what the meeting was about, and not feeling able to say things. However, all were very happy with the one-to-one meetings they had with their social workers (typically around using the Glen or Shared Care) or staff involved in planning their transitions. In these sorts of ‘meetings’ all the young people said they felt able to ask questions and say what they felt.

### 2.5.2 Research evidence

There is some evidence from studies of children’s participation on factors which can facilitate effective involvement of children in decision making, both in decisions regarding their own care and in service development (Cavet and Sloper, 2004a, 2004b):

- A listening culture among staff so that children feel valued and respected, able to express their views at any time, that their views will be listened to and acted upon.
- Clear information about choices available to them, whether in relation to individual care or to decisions regarding service development. Information about what their participation will involve and what will happen (for example, in meetings).
- Flexibility and a choice of ‘methods’ of participation, for example, individual interviews, group methods including fun and social activities, questionnaires, less traditional methods such as drawing and drama.
- Children and young people having a say in the topics for consultation, so that they can raise issues that are important to them and guard against the focus on ‘trivial’ topics.
- Inclusion of all disabled children and young people requires specialist supports for those with communication impairments, language or sensory difficulties.
- Feedback about the results of consultation and any changes that have or have not happened.
- Development of children and young people’s participation requires resources: staff training, staff time, support for staff and children to develop skills and confidence, planning for participants’ special needs, building links with decision makers so that children’s ideas are taken up, addressing organisational culture, structures and processes.

Research on partnership between parents and professionals points to the importance of professionals recognising and acknowledging parents' own expertise on their child (as suggested by professionals in York). The need to recognise and clarify the different and complementary roles, including different skills and knowledge bases, of parents and professionals and to identify shared concerns and common purposes is highlighted in research (Cunningham and Davis, 1985; Dale, 1996). Dale's 'negotiating model' of parent-professional partnerships provides a useful framework for understanding and taking forward parent involvement.

### 2.5.3 Views on how to move forward

Staff recognised that a culture change was needed for family involvement in services to become the ‘norm’ rather than the exception.  They suggested setting up a working group to coordinate parent and child involvement in services.  They also felt that more research was required on the needs of agencies in relation to involving children.  Other suggestions from staff included involving parents in staff training sessions, and looking at what skills and knowledge on child involvement are already available in services and sharing these across agencies.

A number of current developments were identified which could be built upon to facilitate child and parent involvement.  These included: parents being trained to do ‘consultation’ with children in Sure Start; children’s involvement in reviews and in short term breaks; some schools doing annual reviews at the child’s home where the environment can be more comfortable for parents and children; the RAP group; a ‘Young People’s Champion’ and Youth Parliament.

Parents had mixed views about parent and child involvement in services.  One parent had felt empowered by their involvement in a parent action group (Autism in Mainstream Schools – AIM) that had campaigned for changes in services.  Others felt that driving change should not be their responsibility since they did not have ‘the time or energy to fight for services that should be there in the first place’.  Others again praised child-centred approaches to annual reviews with specific reference to the specialist speech and language unit at Haxby Road School.  There was also some disillusionment amongst parents about consultation and whether parents’ views were seriously taken into account when implementing changes to services.

### 2.5.4 Recommendations

- There are already a number of initiatives in York which are involving parents and children in services.  It would be useful to bring together information about and learning from these different initiatives and assess to what extent disabled children, especially those with communication impairments or complex needs, are being involved and what needs to be done to promote their involvement (the recently set up Involvement Group could coordinate this).

- At the moment, the Involvement Group focuses on children's involvement, the Trust should consider what mechanisms might be put in place to ensure that involvement of parents with disabled children is facilitated and monitored.

- Joint training for staff should include a focus on promoting parent involvement. Contact a Family (www.cafamily.org.uk) has produced information packs on promoting parent participation for both parents and professionals which could be helpful in this training and Dale's (1996) work also provides a useful basis for discussion of partnership working.

- Professionals' suggestion of involving parents in staff training should be pursued. Involvement of parents in staff training is growing in many areas, for example SNIP, a parent support organisation based in Edinburgh, has developed a programme of training for care coordination and key worker services using parent trainers. However, we are not aware of any evaluations of such activity.

- It will be important to feedback to parents and children the results of this consultation and the actions that the Trust is taking.

## 2.6 Outreach/community-based services

### 2.6.1 Gaps and areas for change

Service providers felt that there was a gap in outreach support and community-based services for families and that building based services may be more effectively delivered in the community to prevent wasted appointments. The development and maximum use of Integrated Children's Centres to provide expertise close to home was seen as having good potential. It was noted that there was a need to ensure that family support services such as Homestart were in place to enable families to get to community services and enjoy normal family life.

### 2.6.2 Research evidence

The benefits for families of services in which professionals visit families in their own homes, such as Portage and key worker services, are well-established. A review of evidence on early intervention for disabled children concludes that some of the characteristics of the most effective programmes are that they are family-centred and delivered in community settings (Guralnick, 1997).

Integrated Children's Centres are a new development and so there is little research evidence on their effectiveness in providing a base for support for families with disabled children. Existing evidence on the benefits of home visiting services suggests that these could provide a link to the services based in an Integrated Children's Centre and that outreach to vulnerable families would be an important function of the Centre. There have been some evaluations of building based services that provide a range of services for disabled children and these point to the importance of the development of the relationship between parents and staff as a prerequisite for parents' acceptance of services, continuity and consistency of staff over time, parent involvement, accessibility and availability of care in a physically convenient location with reasonable waiting times, and provision of reliable transport where needed (for example, Green and Evans, 1982, 1984; Baine *et al*., 1995).

### 2.6.3 Views on how to move forward

Many of the ways forward identified by staff in relation to outreach support and community-based services replicate those suggested for improving multi-agency working in the city, such as co-location, a multi-agency resource centre, protected time to network with other professionals, and staff training. In relation to staff training, professionals wanted this to include training of volunteers (which would require funding) and also involve parents. Poor communication – both between professionals working with a family, and between professionals and family members – was viewed as a barrier to outreach and community-based support, and training could help to address this. It was suggested that family literacy is a factor in the need for outreach support and one that needs to be addressed by such support.

Improved communication between mainstream and special schools, better systems for equipment to be available quicker (for example, for children with life limiting illnesses) and improved resources for training were all seen as important factors in more effective outreach support.

It was suggested that a multi-agency group with parents/carers and young people, should be set up to take forward the agenda on outreach, and that more information on outreach/community-based services that already exist in the city, and what works well in these and why, would be helpful in deciding how to improve outreach for families with disabled children. The need for administrative support to further develop outreach and community-based services in the city was also noted.

It was noted that there are a number of current initiatives and services which include or can link to outreach support and can be built upon: Portage, Sure Start, Sharing Care, extended schools, paediatric community nursing service which is piloting extended hours and school-based clinics, Children’s Community Team Bereavement Service, Connexions, Integrated Children’s Centres, Early Years, and library services of Books for Babies and Right to Read with looked after children.

### 2.6.4 Recommendations

The suggestion of a multi-agency group, including parents and young people, to take forward outreach and draw together information on existing outreach services should be considered. This group could look at whether and how parents and disabled children/young people access mainstream community services such as Sure Start, and how access to services could be improved for all families with disabled children. This would also link to the work on information provision to families and consideration of how information is provided to families with low levels of literacy.

# Chapter 3 Gaps in Service Provision

## 3.1 Substitute care

### 3.1.1 Gaps and areas for change

*Short term care*
Short term care provision was identified by service providers and parents as a service gap and area for change in York. Whilst the quality of short term residential care provided by The Glen and Sharing Care was widely acknowledged by service providers, it was also recognised that this was not sufficient to meet demand, both in terms of the places available and the length and frequency of breaks offered. They also identified a need for more specialist short term care facilities, including facilities for children with complex health needs and with severe autistic spectrum conditions. Along with providing more short term residential provision, service providers also suggested giving families more choice and flexibility in relation to short term care, including the provision of sitting services. In addition, some service providers wanted the Sharing Care scheme to be extended to cover young people aged over 16 years, and higher payments for carers.

Fifteen parents who completed questionnaires referred to gaps and areas for change in relation to substitute care, and this topic was raised several times in the focus group. Short term residential care was highly valued by parents both for themselves ‘when you need a break, when you are pushed to the limit’, and for ‘space for the whole family’. Parents appreciated the short term care provided by Crossroads or The Glen and wanted more good respite provision. They also wanted more flexible provision; more support workers such as experienced sitters who come to the home; and care on a day-to-day basis.

*Childcare and out of school care*
The availability of childcare before and after school and during school holidays was also noted by service providers as a gap and area for change, especially for children attending special school. It was recognised that parents need out of school care in order to work. Problems with accessing out of school care noted by service providers included unsuitable premises; inflexible school transport services (for children attending mainstream schools); and the need for low staff to pupil ratios, with many disabled children requiring one-to-one attention. In addition staff noted the lack of childminding services for children with special needs.

Good affordable out of school care, both after school and in the holidays, was identified as a significant gap in service provision by parents. Working parents needed this support. As one parent noted:

> We face material deprivation - our souls are our own business - but being prevented from working by simple lack of childcare is unacceptable in 2005.

Parents noted that the lack of out of school care was worse for older children since most schemes seem to stop at about 12-14. Parents said they wanted 'SNAPPY-type' after school and holiday care for older children.

> There should be more help and information available about what happens when your child is too old for 'childcare' but still needs care while you work.

Some parents were using childminding services but these were not always age-appropriate and could be expensive:

> At present using childminders who are fantastic. However, this puts my daughter, almost 16 years old, with a group of under fives!! Also, the cost per hour because of 'special needs' is £5.50 as opposed to £1.50/£2.00 for a 'normal child'.

Another parent noted that out of school clubs needed to have medically trained staff to deal with any health or nursing needs.

*Young people's views*
All the young people who went to the Glen, had a 'Shared Care' family, and/or went to SNAPPY valued this aspect of their lives. They enjoyed the outings, trips to the shops and park, and the facilities that were available (for example, the jacuzzi, particular games). Some of the young people only did these sorts of activities when they came to the Glen or SNAPPY or went to stay with their 'Shared Care' family. The Glen and SNAPPY also provided young people with the opportunity to see their school friends out of school. All those using these services talked about them as positive things *for them* as opposed to them being a means by which their families had a break. Almost all those who went to SNAPPY wanted more SNAPPY-type clubs for them to go to.

### 3.1.2 Research evidence

*Substitute care which gives parents a break*
A break from caring is one of parents' most frequently reported needs (Beresford, 1995). Parents who are satisfied with short-breaks believe they are important in helping them to continue caring for their child at home (Beresford, 1994; While *et al.*, 1996). Highest levels of satisfaction have been found for family-based short term

breaks (Beresford, 1995) but some families and children prefer residential provision, particularly where nursing care is required. Research has shown that short term care services are associated with significant reductions in levels of stress among mothers with a disabled child, at least in the short term (Chan and Sigafoos, 2002).

The most common area for parental dissatisfaction with short-term breaks is the amount of breaks available, especially at weekend and school holidays, and lack of flexibility and choice (Beresford, 1995; Robinson and Stalker, 1991).

Sitting services are important in providing an opportunity for parents to go out together or with their other children. However, little is known about the extent and nature of this provision. There is evidence that day care which the disabled child enjoys is as popular, or more so, than traditional overnight stay, whether in a residential unit or with another family (McConkey and Adams, 2002; Tarleton, 2002).

Certain groups are less likely to be accessing short term care. Children for whom provision of short-term care is most inadequate include: children with complex health needs, children with challenging behaviour, children from minority ethnic families and children with autistic spectrum disorders (Flynn, 2002; Hatton *et al*., 2002; Tarleton, 2002; Townsley *et al*., 2001).

*Enhanced payments for carers*

Enhanced payments for carers have been used in a number of areas to attract carers for ‘hard to place’ children. The evidence is that enhanced payments improve stability of placements, attract people with greater caring experiences and skills, engender greater commitment from carers, and reduce waiting lists for children with complex needs. In addition to enhanced payments other costs can be involved such as: adaptations to homes, extra heating costs, provision of aids and equipment (Heslop *et al*., 2003). However, spending on enhanced short-breaks may well be offset by savings in other budgets if these children require less residential and hospital care.

*Children and young people’s experiences of short term care*

There is less evidence on the effects of short term break services on disabled children and young people’s quality of life. In general consultation studies with children suggest that most enjoy their breaks but a minority have negative experiences and are unhappy. It is not clear what characterises these children and the services they receive (for example, Minkes *et al*., 1994; Prewett, 1999).

*Substitute care which enables parents to work*

Mothers with disabled children are much less likely to have paid employment than other mothers (Beresford, 1995). Although not all mothers of disabled children want to work, around a third of mothers not working would prefer to have a job (Beresford, 1995). For parents of disabled children there are a number of barriers to employment and these include a lack of appropriate child care and the failure of mainstream child care services to provide for disabled children (Kagan *et al*., 1998; Shearn and Todd, 2000). Research on the experiences of parents who do manage to work has found the following features of childcare are important:

- It is suitable for the child's needs.
- It is affordable.
- It is available before and after school and in the school holidays.
- It caters for young disabled people who are older than the usual age range for which 'childcare' is provided (Kagan *et al.*, 1998; Shearn and Todd, 2000).

### 3.1.3 Views on how to move forward

Parents and professionals agreed that local short term residential care provision needs to be developed in order to reduce the number of families taking up residential placements for their children outside the city. Suggestions included extending the services provided by the Glen and Sharing Care with longer and more frequent breaks, increasing the number of specialist foster placements and introducing a specialist sitting service. Improving rates of pay for Shared Care carers was seen as a possible way of addressing the shortage of carers within the Shared Care scheme. There was also agreement that a short term care facility was needed in York which provided breaks for children with severe autistic spectrum conditions.

*Out of school provision*
In relation to out of school provision, both parents and staff felt the way forward was to provide after school *and* holiday clubs in special schools. For children attending mainstream schools, in some cases improvements in the accessibility of out of school clubs was necessary. In addition, transport services needed to be more flexible allow children to attend the out of school club at their school.

However, some parents pointed out that there will still be a gap in out of school provision for older children, since after school and holiday clubs are based within primary schools and not secondary schools. It was also suggested that the problem of caring for and occupying children in the long school summer holiday would be partly alleviated by schools adopting a four term year, thereby reducing the long summer break.

Participants in the consultation identified a couple of current developments taking place in York on which developments and improvements in substitute care could be built. First, SNAPPY is in the process of setting up a pilot after school club for older children at Applefields. Second, consideration is being given to opening an out of school club at Hob Moor Oaks when the new school is built.

### 3.1.4 Recommendations

- To review the number of specialist childminders in York and map this against potential demand. If necessary, seek to increase the number of childminders available.
- To review out of school provision for 12-18 year olds in York and to consult with families about the type of provision they require.
- To review short term break provision for families with a child with an autistic spectrum condition.
- To create out of school clubs at Hob Moor Oaks and Applefields which provide out of school care before and after school and during the school holidays.
- Transport services to introduce greater flexibility in terms of *when* children are collected from school and *where* they are taken.
- To increase funding to Shared Care to allow increases in payments made to carers and to expand its sitting service.

## 3.2 Information

### 3.2.1 Gaps and areas for change

A number of aspects of information provision were identified as gaps and areas for change in York by both service providers and parents. Service providers felt that a service directory was needed to signpost parents to support services, sources of funding, and sport and leisure services that are accessible for disabled children. They also felt that information was needed about the role of new initiatives, such as Connexions. Presentation and dissemination of information was identified as important, including the need to ensure information reaches families who are socially isolated or socially excluded.

Nine parents who completed questionnaires and parents in the focus group identified information gaps for themselves and their children. They felt that information provision was *ad hoc* and disorganised: ‘everything seems bitty – you hear or get to know of one thing from somewhere, another thing from somewhere else’.

Information about what happens when young people get older and leave school was needed for parents and young people themselves, including information about colleges, careers and independent living. Information for young people should be accessible for them and explain things 'in their own terms'.

As with professionals, parents also wanted information about a range of both specialist and mainstream services, including benefits, clubs and support groups, leisure, sports and play facilities, summer schemes, nurseries, childcare, and options for care for older children when parents work. Information about accessibility of local facilities was also needed.

Parents also felt that a service directory would be useful, but they felt that a directory on its own was not enough, they also wanted a single point of information they could access to get information about any aspect of their child's life, with someone who would act as an information coordinator.

One parent noted the need for training for parents about benefit rights and direct payments.

*Young people's views*
We talked to the young people attending special school about the information they had received about moving sites (from the Acomb site to the Burnholme site) and, among the older young people, about leaving school. Most young people we talked to said they knew what was happening about moving sites though a couple still had anxieties about changing school site and wanted to visit the new [Burnholme] site again. In terms of leaving school, the young people were happy with the information they had been given. With respect to young people in mainstream education there seemed to be less satisfaction with the information they had about post-16 options.

### 3.2.2 Research evidence

*Information for parents*
Written information can improve how informed parents feel. However, its effectiveness is dependent on the type and way information is provided (Quine and Pahl, 1989; Mitchell and Sloper, 2000). A parent generated model of good practice in terms of information provision identified three facets:

- Short directories of local services and support networks, which are regularly updated.
- More in-depth and informative booklets covering local and national services, and;
- Support from locally based facilitators or key workers to guide parents through the information.

Information should be clearly written, in an attractive format with an easy to use index, and should include: multi-agency information covering both specialist and community wide services, planning for the future, explanations of the roles of different professionals and agencies, and everyday advice. Parents' involvement in the design of information helps to ensure that it is attractive, accessible and contains the range of information they require. A useful account of the production of a 'signposting' guide to local services, and its use by parents and professionals is provided by Wessels and Bagnall (2002).

*A worker to facilitate information provision*.
Research on parents' experiences indicates that written information on its own is not enough. As noted above, parents want to receive information face-to-face from a professional who will guide them through it. A named worker with whom they have an ongoing relationship is the preferred source of information (Mitchell and Sloper, 2000).

*Information for children*
A number of sources of information are required to meet children's information needs (Beresford and Sloper, 1999; Children's Society, 2001). Children identify parents themselves as important information sources, so ensuring that parents have access to information is crucial for children as well. Other sources include health professionals, teachers, friends, other disabled children, written information, and the Internet. Children identify a number of issues to be addressed:

- Professionals taking time to listen to them and not just talking to their parents.
- The importance of using appropriate communication aids to enable all children to communicate.
- Age appropriate information, in accessible formats to suit the child's needs.
- Provision of opportunities for contacts with other disabled children.

*Different forms of information provision*
There is little literature on effectiveness of different forms of provision of information. In some fields, for example work on medical conditions, information media such as audio or video materials are increasingly being used. However, as yet there has been little research on the use of such media for disabled children and their parents.

*Help lines*
Voluntary organisations often provide interactive telephone help lines offering information and support. Research on the use of such help lines, for instance for adults with cancer, suggests that they are increasingly used to obtain relevant information (Anderson *et al*., 1992). Contact a Family provides a help line for parents with disabled children and other voluntary organisations concerned with specific conditions also provide such a service. However, as yet there has been little evaluation of these help lines.

*Parent held records*
Parent held records with special add-on sheets for disabled children have been instituted in some areas as a way of improving provision of information to parents. However, evidence of their use and effects is equivocal. Not all parents use the records. Those who do value them as a means of recording factual information, but they do not appear to have any effect on parents' perceptions of their child's health care or on communication between families and professionals (Moore, 2002). Clearly parent held records alone will not meet all parents and children's needs for information.

*Computers and the Internet*
Internet based networks can provide families with disabled children with access to a number of resources: information, interaction with others who share their experiences, interaction with professionals (Shank *et al*., 1999; Soutter *et al*., 2004). As yet, there has been little UK research on the effects of access to information through computers for disabled children and young people and their families. However, one example is evaluation of a project in which 75 boys with Duchenne Muscular Dystrophy and their families were provided with computers with email and Internet connectivity (Soutter *et al*., 2004: The Golden Freeway Project). Here one of the key benefits of having a computer was it enabled greater access to 'formal' sources of information as well as 'informal' information through contact with other families.

While the Internet is potentially a useful as a source of information and a useful means by which information can be provided (and updated) for disabled children and their parents, inequalities in access will have to be addressed. Figures on Internet access show marked social inequalities. Data from the National Statistics Omnibus Survey show that at the end of 2000 only 27 per cent of adults living in households headed by an unskilled person had access to the Internet compared with 78 per cent of those in households headed by a professional (Holloway and Valentine, 2003). Given that families with disabled children have lower incomes than families with non-disabled children (Beresford *et al*., 1996), it is likely that they have lower rates of access to the Internet.

*Other parents and children as information sources*
Parents identify contacts with other parents of disabled children as useful sources of information, and children and young people say that they would like to be provided with more opportunities to have contact with other disabled children, particularly those with the same condition (Beresford and Sloper, 1999; Beresford, 1995). Research on parents' views of the benefits of support groups points to exchanging information as a key benefit (Rees, 2002; Solomon *et al*., 2001). Similarly, disabled children and young people identify other children in the same position as themselves as an important source of information (Beresford and Sloper, 1999). However, short term funding and lack of financial security are problems which tend to threaten the sustainability of such groups and better forms of support are needed to ensure that they can carry out this key role (Rees, 2002).

*Communication with professionals*
Communication between professionals and parents and children is an important factor in information provision. Evidence on this is provided in Section 2.3.

### 3.2.3 Views on how to move forward

*Directories*

Professionals felt that information provision should have a wider focus than just the three main services of education, health and social services and should included a directory of leisure activities accessible to disabled children and young people. Web-based directories were favoured since these can be updated frequently.

Parents also said they wanted a directory of services that included all aspects of caring for a disabled child from information about education, health and social care services to information about social and leisure opportunities, transport, and what happens when a child with special needs grows older and leaves school. Information about accessibility of services and contact telephone numbers should be included. Parents saw the value of a web-based directory in terms of keeping information up to date. In addition, it would enable signposting to other sources of information through web links and could also include a section where parents could post notices and questions to one another as well as network. However, parents felt a printed directory would also be needed for families without internet access. Parents felt there should be someone with the job of coordinating information provision to families with a disabled child living in York.

*Information facilitators*

Parents also wanted a professional, such as a keyworker, to support the provision of information to parents. They felt that regular contact with this keyworker would help to ensure a family’s ongoing information needs were met and they were kept abreast of things like benefit changes. It was suggested that the Early Support Programme in York could be used as a template for the provision of information.

*When information should be provided*

Parents felt that information should be provided at the point of diagnosis, when first coming into contact with a service and then in an on-going process.

*One stop shop model*

A suggested solution to meeting information needs made by professionals was a Disability Resource Centre 'owned' by families with parents working alongside professionals and voluntary agencies.

A single point of information was also desired by parents. One suggestion was for a model similar to the Citizens Advice Bureau where clients can either phone up or visit. Parents suggested that a central location for this ‘disability resource centre’ was York central lending library. However, after some discussion it was felt that there might be more scope for a resource centre in premises on the outskirts of the city, where there are good public transport links and parking facilities, such as at a Park and Ride facility like Monks Cross. Parents did not want overall responsibility for the running of this centre, but wanted to work alongside professionals in establishing a ‘focusing point’ for families. As well as providing an information point for families, parents wanted this resource centre to include computer facilities with internet access, meeting rooms for training sessions, support groups, social gatherings, etc, and a 24-hour helpline. Above all parents felt this resource centre needs to be child-friendly with facilities to occupy older children (pool tables and pinball machines) as well as young children (play equipment and an enclosed outside play area), and a ‘quiet’ space for everyone. It was felt that such a multi-purpose resource centre would not only serve as a single information point, but also support contact between parents (who are a key source of information and support to each other) and help to promote a sense of community amongst families with disabled children in York.

Finally, participants noted that the Children’s Society is currently conducting the RAP project which is working with young people (18 -25 years) to identify their information needs. The intention is to develop a web-based information resource. This might be a useful model in terms of information provision to younger disabled people.

### 3.2.4 Recommendations

- An information directory for families with a disabled child living in York is required. This needs to contain information about specialist statutory, voluntary sector and mainstream services as well as information about other local facilities which may be used by families. Print and web-based versions to be need to be produced. This directory should be written by parents, or parents should be strongly involved in its development and content.
- To create a Disability Resource Centre, possibly located within an Integrated Children’s Centre. A Disability Resource Centre provides a means by which information can be accessed, pooled and shared amongst parents and professionals. Parents and children and young people should be involved in the development of a Disability Resource Centre.
- To look to extend the keyworker service currently provided through ESP to families with older children.
- To identify ways of supporting the creation and maintenance of groups for parents and for children and young people.

## 3.3 Family support

### 3.3.1 Gaps and areas for change

Service providers noted that services should be responsive to the family's needs. The parent focus group and three parents completing questionnaires wanted services to recognise that all family members are affected by the child's disability.

*Parent support*
In addition to providing substitute care, service providers identified other gaps or areas for change in relation to parent support services in York. These included:

- Proactive support to prevent stress and crises.
- Advocacy.
- Skills training, including skills for managing stress and training for parents on managing their child's condition.
- Emotional support, including enabling families to meet with other families and reduce social isolation, and individual emotional support in the home. It was felt that parents whose children were in mainstream schools were particularly at risk of isolation.

Parents also identified these sorts of gaps:

- *Skills training* came up a number of times in the focus group and three parents who completed questionnaires referred to it. The need for training over and above normal parenting issues was noted, including training focused on ways to help their child, how to deal with a child's developing awareness of their condition and how to deal with a child's temper.
- The potential for groups to provide opportunities to gain *emotional support* from others was noted by one parent, but a need to provide a crèche was identified:

> When there are meetings/get togethers with families etc., it would be ideal if there was a creche (I know it may be difficult) as I am a single parent and sitters are difficult to get. My youngest child is quite a handful and needs a lot of attention so if I take him with me there are no opportunities to talk to others as I have to be with him all the time!'

- *Advocacy* to help ensure that their child' s rights and needs were met was noted in the focus group.

*Sibling support*
Both service providers and parents felt that more needed to be done to providing support for siblings of children with special needs. (Please note these are the views of parents and professionals and not siblings themselves.)

Service providers identified the need for on-going sibling support, rather than one-off group meetings.  Four parents who completed questionnaires highlighted the need for sibling support and this topic was raised several times in the focus group.  Parents wanted emotional support for siblings through an age-appropriate support group or network to enable their other children to spend time with siblings similar to themselves 'who really know how it feels', to 'help them understand', and to 'know that they are not alone'.  For one parent, providing this support would help ease their own anxiety about the effect on siblings of having a child with special needs in the family.

### 3.3.2 Research evidence

*Skills training*

Sleep and behaviour problems are more common among disabled children than non-disabled children and their management often requires more than ordinary parenting skills (Quine and Pahl, 1989; Wiggs and Stores, 1996; Dekker *et al*., 2002; Quine, 2001).

Sleep and behaviour problems are associated with high levels of stress and irritability for parents (for example, Quine, 1986; Sloper and Turner, 1991).  In some cases sleep problems are caused by physical factors, such as upper airway obstruction or the presence of medical equipment.  However, in many instances the sleep problem is a behavioural problem.  For children, sleep problems are associated with poor concentration and daytime learning, and increased probability of daytime behavioural disorders (Lancioni *et al*., 1999).  However, only a minority of families who have a child with a severe sleep problem appear to receive any help (Wiggs and Stores, 1996).  The situation is the same in terms of behaviour problems.  In a survey of over 1000 parents of severely disabled children, over half said they needed help with managing their child's behaviour and, of these, over 60 per cent said their need for help was not being met (Beresford, 1995).

There is a relatively sound body of evidence that behavioural interventions to resolve 'behavioural' sleep problems are effective and that parents can be trained in the appropriate skills and strategies to carry out an intervention.  What is important, however, is that parents are supported through on-going contact with a skilled professional during the intervention period (Quine, 1993; Wiggs and Stores, 2001; Stores and Montgomery, 2002).  There has been less recent research on the effectiveness of skills training for parents in terms of managing behaviour problems.  However, a review of research published in the 1970's and 1980's carried out by Breiner and Beck (1984) concluded that 'parent training may be an effective means of reducing developmentally delayed children's problem behaviours, improving parents' perceptions of their children's adjustment, and teaching parents a means of promoting positive parent-child interactions' (p.275).

Sleep and behaviour problems are not the only sources of stress in parents' lives, and not all sources of stress are amenable to change but, instead, have to be ‘lived with’ (Beresford, 1994). More generic coping skills training programmes have also been used with parents of disabled children. These programmes seek to help parents identify sources of stress, mobilise support and enhance their coping skills. Evaluations of such interventions show positive improvements in levels of parental stress and emotional well-being, and that these are maintained, at least, beyond the short term (Beresford *et al*., 1996).

Counselling approaches have also been suggested as a means of addressing parental stress. Research is sparse but there are a number of small studies which show evidence of improved psychosocial adjustment for mothers who receive support from parent advisors trained in counselling skills (Davies, 1993).

*Parent support groups*

Contact with other parents is seen by parents as a key source of information and emotional support (Beresford, 1994). Other parents can provide information about local and national support services, benefits, local facilities and activities and strategies for dealing with problems and changes in the child’s condition or transitions (Kirkman, 1993; Rees, 2002; Solomon *et al*., 2001). Parents describe the sort of emotional support they gain from other parents as being unique. However, despite the clear benefit of parent support groups, short term funding and the lack of financial security often threaten the sustainability of such groups and better systems are needed for supporting the development and maintenance of such groups. In addition, care needs to be taken to ensure such groups are accessible and appropriate to all parents, including lower income families and families from minority ethnic groups (Beresford, 1995; Chamba *et al*., 1999; Hatton *et al*., 2002).

*Sibling support*

Research into sibling support is mainly restricted to identification of the sorts of support needs siblings may have as opposed to effectiveness of different interventions. The support needs of siblings include: information support (about the sibling’s disability or illness, how best to help their siblings; how to deal with others’ attitudes towards disability); support to enable them to have a life of their own (typically this means chances to spend time with parents without the disabled sibling and not having to assume the role of carer); and emotional support (Tozer, 1996). Sibling groups are seen as way to meet information and emotional support needs (Tozer, 1996). One study which has evaluated the impact of a sibling support group found positive effects with improvements in sibling relationship, greater confidence in explaining their siblings condition to others and having friends visit the home, and also improvements in communication between sibling and parent about the disabled child (Newson and Davies, 1994). Other research on meeting the support needs of young people reports that a careful balance needs to be struck between the group being able to access specialist information and advice but at the same time being an opportunity for young people to get together informally for social or leisure activities (Beresford and Sloper, 1999).

### 3.3.3 Views on how to move forward

Several suggestions from staff on how to improve the support available to families are dealt with elsewhere in this report. These were to provide families with keyworkers and to build on the support provided to families of children under three years currently being introduced as part of the Early Support Programme (see Section 2.2); to extend the provision of after school and holiday care (see Section 3.1); and to improve access to leisure activities (see Section 3.4).

Other ways forward suggested by staff related to support for parents and siblings included boosting parent and carer support groups, ensuring parents have access to counselling support, and to set up sibling support groups in schools.

Parents highlighted existing services that provide good support to families and suggested using these as a model to extend parent support services in York. Portage was a highly valued service and parents felt the Portage model (that is, on-going home-based support from a single worker by which parents are equipped with skills to work with their child and receive information and emotional support) would work equally well among parents of older children. In addition, the Child and Adolescent Mental Health Service (CAMHS) was valued for the sibling support groups it offers, and its support to families with children with autistic spectrum conditions through the Early Bird scheme and parent information and training courses such as YISPA.

The importance of promoting contact between parents was highlighted by parents. Parents would welcome opportunities to mix with other families, including residential weekend breaks. They would also welcome support for siblings of all ages and agreed that whilst this would require specialist input, support should be provided in the context of ‘fun’ age-appropriate activities. One parent valued the support provided to siblings through the York Young Carers Project, but noted that access depends upon labelling siblings as ‘carers’ which could be a barrier for some families. The hospice movement was also cited as a good model in the way it supports siblings through occasional but regular meetings based around a leisure activity but with specialist input and information also provided. The key priority for parents, however, was for a ‘resource centre’ in York that could provide a meeting point for families, and a place where support for families, such as parenting courses, counselling support and sibling activity groups, are readily available.

### 3.3.4 Recommendations

- To create a Disability Resource Centre (see Section 3.2).
- To identify ways of supporting the creation and maintenance of parent and sibling support groups (see also 3.2).
- To set up skills training programmes (individual interventions) and courses (group based interventions) for parents. These would cover: sleep and behaviour management and coping skills training.

## 3.4 Friends and leisure

### 3.4.1 Gaps and areas for change

*Friends and friendships*
A strong and recurrent theme emerging from our consultations with the three stakeholder groups is that many disabled children and young people have no or very limited opportunities to meet up with their friends when they are not at school. Among children attending special schools, this isolation is also extended to a lack of contact with non-disabled peers.

Service providers believed social isolation was a significant problem for disabled children and young people living in York. They also identified a number of barriers to enhancing these children's social lives including: a lack social and leisure activities for these children to attend (and which can be attended without parental support), transport difficulties preclude visiting friends or attending social/leisure activities, and school located away from the local community.

Many parents voiced a desire for their child to have chances to meet up with school friends in the school holidays, to have a network of friends, and/or to have more opportunities to socialise with disabled and/or non-disabled peers.

A common theme within discussions about ways of addressing this issue was the importance of supporting and enabling children to have social lives and see their friends without having to be 'taken to' events by their parents and/or supported in participating by their parents. Parents also flagged up the need for more clubs and activities to be available thus offering opportunities for mixing with friends and/or peers. An additional requirement, suggested by a couple of parents, was to increase opportunities for children with similar needs to meet up and be together. This, it was felt, would address their child's sense of isolation and feelings that they were 'different'.

*Young people's views*

Almost all of the young people attending a special school, and a smaller proportion of those attending a mainstream school, did not see their school friends out of school. For those at special school, formal settings such as SNAPPY or Gateway were often the only opportunity they had to see their school friends when they were not at school. One or two young people had different social networks outside of school and mixed with other young people in their street or neighbourhood. However, the majority of young people in special school did not have other friends. Virtually all the young people we spoke to wanted to see their school friends after school, at weekends and in the holidays. They wanted to go to each other's houses, do things together, and to go to clubs and activities together. This was a very important issue for many young people. One young man said he wanted to be at school all the time: 'I always like to be here [Applefields], because I don't get to see my friends when I'm not here'.

*Leisure*

Closely linked to the issue of children's social lives is what children and young people are, or are not, doing when they are not at school. 'Lack of opportunity' is a phrase which sums up the message from our consultations with providers, parents and children and young people themselves in terms of their leisure lives. It is also universally seen as a priority area for change which, if achieved, would have a significant impact on the quality of children's lives.

While service providers tended to speak in quite general terms about leisure opportunities, parents were more specific in terms of the sorts of things they wanted their child to be able to do when they were not at school. These included sport, drama, music, swimming, soft play, going to the park, bowling, going to cafes/pubs, the cinema, youth clubs and 'activity' clubs (for example, Scouts). Service providers and parents all said more leisure activities which could be used by disabled children and young people were needed.

Parents differed as to whether they wanted their child to access mainstream or specialist leisure activities/facilities. In addition, some parents wanted more leisure activities which whole families could use together as a family, while other wanted there to be more activities or opportunities for their child to do things without the family (though recognising this might require some sort of support).

In essence, therefore, there was a clear call for *more* provision and a *variety* of provision which takes account of differences in interests and abilities, and preferences for whole-family or child activities. However, the main point raised by providers was the issue of transport to and from the places where children want to go. Being dependent on parents for transport (due to inaccessible transport or not being able to travel independently) was seen as a key barrier to expanding the ways in which children and young people spend their free time.

*School-based leisure activities*
Though less frequently mentioned, the need for more school-based after school activities, particularly at Applefields School, was raised. The school transport system was seen as a barrier to achieving this. Similarly, children attending mainstream schools experienced difficulties staying on to after school clubs because of the inflexibilities of the school transport service.

*Young people's views*
Overall, the young people we consulted wanted more to do when they were not at school. This was particularly the case for those attending special school.

Many of the young people who participated in the consultation enjoyed sport and wanted more opportunities to do sport (for example, football, rugby, cricket, netball, basketball, weight/fitness training) out of school. In particular they liked the idea of belonging to a club and doing training and playing matches. None of young people attending special school belonged to a mainstream sports club. Most of the young people in mainstream schools were playing sport after school, though it is not possible to gauge whether or not they were members of an actual club.

The young people in special schools were typically only using specialist 'leisure' clubs (such as SNAPPY, Gateway, Phab and the Wednesday sports club at Oaklands Leisure Centre). These clubs were highly valued and the young people wanted there to be more clubs of this nature. It was only the more independent young people who were either attending or expressed a desire to attend a local, 'mainstream' youth club.

Other places that the young people wanted to go were the library, swimming pools, bowling alleys, snooker halls, pubs and clubs. A lack of a means of getting there, not having someone to go with, or needing support to access the facilities were the main barriers to the young people enjoying such places. Some young people had a PACT worker and this enabled them to go to do these sorts of leisure activities. This was an important and valued part of their life.

### 3.4.2 Research evidence

The findings from the consultation on the gaps with regard to social and leisure opportunities for disabled children in York mirror the national picture (for example, Watson and Priestley, 1999; Connors and Stalker, 2000; Petrie *et al*., 2000; Finch *et al*., 2001; Beresford, 2002a). While there have been developments 'on the ground' to promote inclusive leisure services and to increase inclusion of disabled children and young people in mainstream activities there is very little research on how best to support inclusion and to extend and broaden social and leisure activities of these children and young people (Beresford, 2002a).

There are, however, two areas where there has been some research on improving the social and leisure opportunities for disabled children and young people. The first concerns inclusive play and leisure services. Here, three factors emerge as important: training, resources and environment (Newton, 1997; Petrie *et al*., 2000; Thompson *et al*., 2000). Staff training has repeatedly been shown to be a key factor in providing inclusive services. These training needs include: knowledge of medical conditions; self care issues; awareness/skills in providing or facilitating appropriate activities; and dealing with challenging behaviour. In any setting, it is important that *all* staff are trained. In terms of resources, adequate numbers of staff with appropriate skills is essential. Finally, the physical environment should be fully accessible and safe.

There has also been some work looking at promoting inclusion through participation in mainstream activities. Research which has reviewed what, and what does not work, in supporting inclusion has identified three factors (Perry, 1998). First, work to support inclusion has to be intentional. Second, disabled children and young people have to be involved in planning and developing ‘services’. Third, inclusion means participating in ordinary, everyday life – having friends, going out with friends, enjoying family outings – efforts to support inclusion need to focus on these activities.

### 3.4.3 Views on how to move forward

*Professionals’ views*

Professionals participating in the consultation believed that providing after school clubs at special schools would help reduce the social isolation of pupils who return home to neighbourhoods where none of their school friends live. Other suggestions for reducing this social isolation were to facilitate a network of pen pals amongst children with special needs, and to set up a ‘family forum’ and ‘young person’s forum’ where families and young people could get together for shared activities.

Professionals also felt it was important to secure long-term funding for existing services that enable disabled young people to meet up with friends and take part in leisure activities, such as SNAPPY for its special needs play provision, and PACT for its student befriending scheme. They also suggested providing more inclusive play schemes and more specialist activities such as special needs swimming sessions. A directory of leisure services accessible to children with special needs was needed to ensure parents and young people knew what was available.

Employing specialist workers would also help disabled children get to and take part in an activity. Other suggestions were to instigate a ‘disability sports development plan’, and to encourage participation in sports and leisure clubs by introducing ‘taster days’ for young people to try out various leisure activities. Staff training was viewed as crucial to service provision. Staff felt that all workers involved with leisure services (from bus drivers to catering staff) should receive disability awareness training.  It was also suggested that specialist staff training should include training in alternative means of communication, such as using photo symbols.

Suggestions for overcoming the transport problems often associated with accessing leisure activities included making school transport more flexible to allow children to attend leisure activities (for example, attending after school clubs) and to extend the YILTS (York Independent Living Travel Skills) Scheme currently being piloted in York so that more young people are able to use public transport independently.

*Parents' views*
Parents agreed with the solutions put forward by professionals, and prioritised providing secure long term funding for valued services (for example, SNAPPY, PACT) and providing specialist workers to support access to leisure activities. Parents said they would readily 'buy in' to a 'buddy' service.  They wanted any disability awareness training for staff to include 'invisible' disabilities such as autistic spectrum conditions.

Whilst parents would welcome more specialist leisure sessions after school, at weekends and in the holidays for their children, they would prefer these to be open to the whole family.  Parents felt that family swimming sessions supported by specialist staff, for example, would be very popular and generate enough revenue from admission charges to be self-funding.  A suggested way forward was for the council to sponsor (or find business sponsorship for) special family sessions at leisure facilities like *Creepy Crawlies* Adventure Playsite and Family Entertainment Centre, York City Screen, Vue, York Community and Gymnastics Club (Heworth) and York Megabowl.  Parents of older children wanted more opportunities for their children to participate in age appropriate leisure pursuits including outdoor pursuits (for example, climbing, canoeing), team sports and youth clubs.  Another parent felt that libraries could be more accommodating to children with special needs, for whom books can be unsuitable.  They suggested providing a video/DVD loan service free of charge to children with special needs.

Parents emphasised that a lack of information about what leisure opportunities are available and how suitable they are for children with a wide range of special needs, was a key issue.  It was very important that information about leisure opportunities and facilities in York included parent reviews and recommendations.  Parents felt that one of the roles of proposed 'Disability Resource Centre' (see Sections 3.2 and 3.3) could be to act as central point for information about leisure and other services and also to organise or coordinate events and activities for family days out with reduced costs from group bookings, shared transport, and so on.

Another priority for parents was for more after school and holiday clubs to enable children to meet up with friends and take part in leisure activities.  In particular parents wanted more ‘SNAPPY-type’ play provision during the long summer holidays. Parents also highlighted the importance of providing transport to and from after school and holiday activities, since a lot of parents’ time is spent transporting their children to services. Parents were willing to make a contribution towards costs or take responsibility for one of the journeys.

Parents whose children used the PACT ‘buddy service’ valued the positive impact this had had on their child’s social life and it was felt that this service should be extended.

In addition, parents made more specific suggestions about changes that needed to be made. These included:
- Improved changing facilities for children with self-care needs. These need to be suitable for older children/young people.
- ‘Whole family’ changing facilities (older boys not allowed in female changing rooms but mothers reluctant to let them use male changing rooms unsupervised).
- Increased provision for older children who enjoy ‘younger activities’. For example, many commercial soft play areas have an upper age-limit of 12 years; holiday clubs have an upper age limit of 12 to 14 years but may be suitable for an older teenager with special needs.
- Discounts on leisure facilities/activities (for example, bowling, cinema) for families with a disabled child.
- Inclusive sports clubs (for example, inclusive football or cricket club).
- Services and clubs which run for the whole year as opposed to just term times.
- Extra leisure provision in the school holidays and/or improved access/inclusion to mainstream holiday clubs and schemes.
- Accessible building and toilets in places where children’s clubs and activities take place.

### 3.4.4 Recommendations

- To appoint a sport and leisure development officer to develop a strategy, partnerships and services, and to champion the social and leisure needs of disabled children, young people and their families living in York.
- To establish partnerships with private leisure businesses to provide ‘special’ sessions on a regular basis for families with children with special needs. The sorts of facilities families want to be able to use as a family and with other families with special needs children include: cinema, swimming pools, gyms, bowling alleys, soft play areas, snooker and gymnastics.
- To establish partnerships with private/voluntary sector leisure providers or clubs to enable the participation of disabled children in their activities and to provide trained volunteers or workers to support participation. The sorts of clubs and

activities that children want to join are: football, rugby, cricket and netball teams, gymnastics and dance classes, cubs/brownies/scouts/guides, and youth clubs.

- To subsidise costs of using leisure facilities, either through reduced charges and/or a voucher scheme.
- Instigate a council wide disability awareness training scheme for *all* staff working in leisure services, with more specialised training provided to key staff at each facility.
- York libraries to loan DVD/videos free of charge to children with special needs.
- All public sports facilities in York to be accessible, have ‘whole family’ changing facilities, and have self-care and toileting facilities that are suitable for use by older disabled children and young people.
- To facilitate Children's Trust support to the voluntary organisations that work with this group of young people, particularly around funding issues.
- Holiday and after school clubs to run at Applefields and Hob Moor Oaks.
- Based on the findings from the pilot, extend funding for the YILTS scheme.
- Develop greater flexibility in school transport services.
- To include in any Information Directory a section on social and leisure activities including reviews and recommendations by young people and parents. This section, as with the rest of the Directory, should be written in an accessible way.

## 3.5 Transition

### 3.5.1 Gaps and areas for change

Transition can mean lots of different things. It is used to refer to the movement between services, for example, primary to secondary school, or from using children’s to using adult services. It is also used in the context of ‘growing up’ and moving from childhood to ‘adulthood’ and what that means in terms of independence, leaving home, employment and so on. Continuity between services for different ages – ESP to school and young people up to 25 – was highlighted as a gap by service providers. One parent felt that improvements were needed in continuity of workers with individual children. However, the main transition that was discussed concerned leaving school and preparing for ‘adult’ life.

Transition was an issue that was raised by service providers in all three workshops, and was seen as something where changes needed to be made. They spoke of inadequate levels of support for young people and their families during the transition process despite it being a critical time in a young person’s life. There were a number of comments about the lack of coherence and multi-agency planning and working around transition which, it was felt, threatened the outcome of a transition.

It was felt that improvements needed to be made in post 16 years provision and that, at the moment, choices about work, training or education were very limited. Inadequacies in health provision were also described with often no clear route of referral on from paediatrics, or between CAMHS and adult mental health services.

A sizeable proportion of comments about transition actually concerned inadequacies in adult services, from a lack of supported housing and services to supporting disabled young people to find work and stay in work. None of the parents expressed views on the transition *per se*. A couple believed there was a lack of post school/college employment or training opportunities and supported housing options. In the main, however, parent's views on transition were more about their aspirations for their child in terms of him or her achieving as much independence as possible.

*Young people's views*
The KS4 young people at Applefields we spoke to were all very happy with the support they were receiving as they planned for what they would do when they left school. Responses on the questionnaires returned by pupils in mainstream schools suggest that this might be more of a gap in mainstream schools, with a lack of information about future options and not having someone to help with planning being reported by (a minority of) respondents.

It should be noted that at the moment the Learning and Skills Council are carrying out a strategic area review on three to ten year planning for young people aged 16 years and over in York. In addition, the York Scrutiny Panel has just completed a scrutiny on post-16 transition. In addition to the recommendations made in this report, the findings from both these activities should be used to inform any developments.

There are a number of initiatives currently taking place in York which indicated that York is already committed to improving transitions for disabled young people. A multi-agency transitions group has been set up and there are practitioner-based 'transitions champions' (social workers). York Independent Living Travel Skills Initiative (YILTS) to get young people (year 11) out of taxis and on to public transport is currently being piloted. As with the rest of the country, York is taking on board Person-centred Planning for transition. More specifically, there has been the creation of a part time physiotherapist post for young people aged 16 to 25 years, and Barnardo's and the Children's Society are working on developing a video about transition.

### 3.5.2 Research evidence

Most research evidence about transition concerns the experience and outcomes of transition and there are clear gaps when it comes to trying to understand what works, for whom and in what circumstances in terms of the transition of disabled young people to adult status, and in terms of service transition. In addition, there is virtually no research which includes long-term follow up of young people who have been through transition from child to adult services. Finally, few research projects have managed to take a complete view of transition, instead focusing on one aspect (for example, leaving home, transfer from paediatric to adult clinics). However, there is evidence which shows the different aspects of adult status are linked to each other (Forbes *et al*., 2002).

There is strong evidence from all stakeholders that for most disabled young people the process of transition from child to adult services is problematic (see Cope, 2003; Hendey and Pascall, 2002; Morris, 1999, 2002; Hirst and Baldwin, 1994). Key problems with transition services are: lack of an holistic approach; insufficient attention paid to the concerns/priorities of the young person; lack of multi-agency working; lack of specialist transition services and workers; lack of appropriate service/provision onto which the young person can transfer (see Cope, 2003; Dean, 2003; Forbes *et al*., 2002; Heslop *et al*., 2002; Morris, 1999, 2002; Fiorentino, 1998; O'Sullivan, 1998; Pownceby *et al*., 1997).

Research has shown that it is rare that the outcome of transition services is that a disabled young person achieves 'adult status' in terms of work/financial independence, living away from home, social/sexual relationships (Hendey and Pascall, 2002; Heslop *et al*., 2002; Hirst and Baldwin, 1994). In addition, transition services do not pay any/adequate attention to the things that are most important to (disabled) young people – friendships, social life and leisure (Heslop *et al*., 2002; Morris, 1999). Young disabled people (and their parents) are typically not properly involved in decision-making (Cope, 2003; Heslop *et al*., 2002; O'Sullivan, 1998). For many young people, the outcome of their transition seems to be very much down to the role played by parents and their expectations (Hendey and Pascall, 2002; Morris, 2002; Pownceby *et al*., 1997).

There is some evidence, through limited in its scope and quality, on what need to be in place or what needs to change in order to improve transition services and their outcomes. Certain aspects of service structure and the process of service delivery has been identified as factors which support continuity in the transition from child to adult services (Forbes *et al*., 2002; Heslop *et al*., 2002; Ward *et al*., 2003). At an organisational level these include:

- The need for specialist services and skilled staff dedicated to the transition period.
- The need for multi-disciplinary and multi-agency working.

In terms of service delivery, the following factors were found to promote continuity:

- Adequate preparation.
- Active case management shared across agencies.

- Strong therapeutic relationships between practitioners and the young person and their family, and independent advocates.

Forbes *et al*. (2002) also identified components of good practice regarding working with young people and these included:

- Specific, specialist service provision.
- The development of self-management skills and psychosocial development covered in the service.
- Meaningful involvement of the young person through the provision of information and involvement in decision-making.
- Support for changed relationships with parents/carers.
- A focus upon young person's strengths for future development.

More recently published research has also noted the need to ensure the young person has an adequate system for communication (Dee and Byers, 2003), and the value of peer mentors (Bethell and Harrison, 2003) to support the process of transition from childhood to adulthood.

While there is less evidence with regard to good practice with parents and carers, the following components of good practice have been identified (Forbes *et al*., 2002; Heslop *et al*., 2002; Morris, 2002):

- Support for adjustment to changed relationships with young people.
- Parental involvement in service planning.
- A family centred approach.
- Provision of information.

### 3.5.3 Views on how to move forward

Professionals who participated in the consultation noted that little headway could be made in preparing a young person for adult life until significant improvements were made to the 'black hole' of services and opportunities available to young adults once they leave school. There was a feeling that a 'corporate' lead was needed to pull together all the resources for post 16s, and to plan and develop innovative ways of meeting the future employment, housing and other needs of disabled young people, since 'there are lots of kids coming through that may need this.'

In terms of the transition itself, staff felt that a coordinated, multi-agency approach to transition planning and delivery was essential, and there were 'pockets of good practice' to build upon. It was suggested that keyworkers, supporting young people and their families through the transition period, should coordinate the different services involved in helping a young person to leave home, find employment or

further training, and become as independent as possible. Staff noted the importance of providing consistency during the ‘handover’ period.
Other more specific suggestion included:

- To provide an advocacy service to speak up for and support young people and families.
- To develop a direct payments policy for young people with clearly identifiable funding.
- To provide training, information and support to Connexions staff working with disabled young people.
- For the City of York needed to build job opportunities for disabled people into its economic development plan. (This is something that Leeds City Council is currently doing.)

Parents were also keen for a transition champion to work behind the scenes to improve services and opportunities available to their children, and for an advocacy service to speak up for and support young people and families.

Parents felt strongly that adult services (for example, health, residential short term care) were often inappropriate for their children and ‘young adult’ or ‘youth services’ should be provided for young people aged from 14 to 21 or even 25 years.

Parents felt that information (for parents and young people) about transition and the options available (in terms of training, employment and housing) needed to be improved. A time scale guiding parents through the various processes would also be helpful. Parents believed a video featuring young people who are going through or have recently gone through transition would also be another useful resource for parents and young people. Parents also wanted a ‘keyworker’ to coordinate information provision and support over the transition period. Parents wanted to have a choice about who supported them and their child through transition.

### 3.5.4 Recommendations

Two of the key ways to improve the transition process are improvements in multi-agency working and information provision for families. Recommendations with regard to both of these points have been made in earlier sections. In addition, the following recommendations are made:

- To review training and employment opportunities available to young disabled people in York.
- To review independent and supported living schemes in York against data on future need.
- To build on existing practice in York around transition, and for developments to be informed by the recommendations of the Scrutiny Panel.

- To review provision for young disabled adults within adults services with regard to health care (including mental health) and short term care.

## 3.6 Issues concerning children's health and well-being

This section focuses on a number of very specific issues which are all concerned with children and young people's health and well-being and which were raised in the course of this consultation exercise.  This section does not, therefore, deal comprehensively with all possible issues related to children and young people's health and well-being.

### 3.6.1 Gaps and areas for change

Some specific gaps in services relating to children and young people's health and wellbeing were noted by service providers and parents.  Both identified gaps in relation to inpatient and A&E provision which could successfully meet the needs of children with autistic spectrum conditions or learning disabilities.  The other gap noted by service providers centred around emotional support and counselling services for disabled young people.  Parents also identified the need for more input from physiotherapy and speech and language therapy services to maximise their children's potential.

*Young people's views*
We asked the young people if they felt they had someone to talk to when they were upset or worried.  All felt they could talk to one of their parents and many also said they would talk to their friends and someone at school or their social worker.  A small proportion said they would like to have someone else to talk to, and this included young people in mainstream and special education.

### 3.6.2 Research evidence

While these issues, again, are not exceptional to York there is no evidence base which can be used to inform how best to respond to these two issues.

### 3.6.3 Views on how to move forward

Staff noted that local implementation of the Children's National Service Framework, particularly the development of Integrated Children's Centres, was driving the agenda forward for improving children's and young people's health and well-being.

*Improving access to and the experiences of using A&E and other health services*
Professionals participating in the participation suggested that Selby and York Primary Care Trust (SYPCT) should develop a plan to make their services accessible to all children, included those with autistic spectrum conditions or severe learning difficulties.

*Emotional well-being*
Professionals suggested a peer mentoring service for disabled young people would be useful. It was also suggested that a counselling service (for example, through the York Youth Work Project and/or the Youth Enquiry Service) should be available in schools.

### 3.6.4 Recommendations

Recommendations made in earlier sections on workforce and staff skills are applicable to the issues of A & E services and increasing access to therapies.

- In addition, at all times there should be a member(s) of staff at York District Hospital who is skilled to work with children and young people with learning difficulties, autistic spectrum conditions and/or cannot use speech to communicate.
- Workforce training for staff working closely with disabled children and young people to include emotional support/mental health issues.

## 3.7 Equipment and housing

### 3.7.1 Gaps and areas for change

At two of the three service provider workshops gaps or difficulties were described concerning equipment and housing adaptations services and the availability of adapted housing. First, inadequate levels of funding within community equipment and housing departments resulted in unmet need. In addition, middle-income families were flagged up as being increasingly required to self-fund equipment and adaptations. Second, the lack of family-sized adapted or accessible housing within the social rented sector was identified as a gap by service providers.

### 3.7.2 Research evidence

Research suggests that there are considerable levels of unmet need in terms of community equipment and housing among many families with a disabled child (Beresford, 2002b; Beresford and Oldman, 2002). In addition, the lack of suitable housing within the social rented sector is a nation wide issue (Beresford and Oldman, 2002). It is also clear from these and other research projects that there are a number of problems with regard to housing and community equipment provision and that, while not raised within the confines of this consultation exercise are, nonetheless, going to be relevant to York.

There is no body of evidence with regard to resolving these issues. However, practitioners taking part in projects on ways to improve the housing and community equipment needs of disabled children (Beresford and Oldman, 2000; Beresford, 2002b) have identified possible local solutions to address the issue of underfunding. These include: better collection of data with regard to local levels of need to inform strategic planning and budgeting; ring-fenced money for adaptations for disabled children and pooled budgets with health; and, for families ineligible for full DFG grants, very low interest loan schemes. Reducing bureaucracy and inefficiencies could also mean more money is available for grants. Ways of saving money include recycling equipment, using ‘real’ competitive tendering for services from architects, builders and so on, self-assessment for low cost equipment or adaptations, and shared assessments between housing and social service departments.

A solution identified by housing practitioners with regard to the lack of adapted, family-sized housing in the social rented sector is to not allow family members to inherit council tenancy of adapted properties and, rather, to be offered an alternative property.

### 3.7.3 Views on how to move forward

Staff suggested the way forward was for joint funding, with budgets pooled on a multi-agency basis. It was noted that communication aids and other forms of community equipment are already jointly funded and this might provide a template for the funding of other specialist equipment.

Staff agreed that the application process for equipment and housing adaptations needs to be streamlined and speeded up, and clear protocols established within and across agencies about the application process. It was noted that the government review due in May 2005 *may* improve the funding of housing adaptations.

Another solution put forward by staff was for low interest loans to be made available to families so that families can pay for community equipment and housing adaptations.

### 3.7.4 Recommendations

- If the current government review does not abolish the means test for the Disabled Facilities grant (DFG), to set in place a very low interest loan scheme for families ineligible for a full DFG.
- Review current practices re tendering for housing adaptations work and seek greater competitiveness with savings directed into the housing adaptations budget.
- Offer self-assessment for stand-alone low cost adaptations (for example, grab rails, ramps) and ‘simple’ community equipment items with saving directed into the housing adaptations and community equipment budgets.

# Chapter 4 Conclusions

## 4.1 Introduction

The purpose of the consultation was to identify gaps in services and needs for change in key areas of service provision, and priorities for implementing change in York in order to improve outcomes for disabled children and young people and their families. The consultation identified a number of areas of good practice and valued services in the city. The short term care provided by the Glen and Sharing Care, social work support, Portage, schools, the Child Development centre and leisure opportunities provided by SNAPPY and PACT were all highly valued by parents and young people. Nevertheless, many gaps were identified and some valued services were restricted by lack of resources and/or short term funding.

The brief for the consultation placed particular emphasis on the identification of opportunities for integrating services and changing working practices. Research shows that such changes can be difficult to implement and may be resisted by staff. However, it was very clear from the consultation with professionals that there was great enthusiasm among staff for increased multi-agency working and a sound basis on which to build. The fact that York is a small city means that many professionals know each other and the consultation itself provided a forum for staff to exchange views. There was a strong sense of wanting to develop and improve services and this provides an ideal opportunity to take forward plans to increase integration of services.

The purpose of integrating services is to improve outcomes for children and families. The *Every Child Matters* outcomes framework defines the five outcome areas of being healthy, staying safe, enjoying and achieving, making a positive contribution and economic well-being, as the basis on which services should plan to improve the life chances of children in their area. It is recognised, in government and in services, that more work is needed on the ways in which these outcomes are interpreted for disabled children and questions such as 'how do we view being healthy for a child with a degenerative condition?' must be addressed. It is not within the scope of this report to explore these questions in detail, although research is beginning to investigate them (e.g. Rabiee *et al*., in press). However, in defining the key issues coming out of the consultation we will suggest how addressing these issues will contribute to disabled children making progress on one or more outcomes.

We also highlight the importance of looking at outcomes for parents. The majority of disabled children are cared for by their parents (Gordon *et al.*, 2000), with services being desired to support the family in that role. Research has shown that parents with disabled children provide extra care, over and above that of ‘the reasonable parent’, and it is with this extra care that they need support (Roberts and Lawton, 2001). We also know that parents with disabled children are particularly vulnerable to stress, which is often produced by trying to meet the extra demands of caring for the child without the necessary resources and support (Knussen and Sloper, 1992; Beresford, 1994). Parental stress in turn impinges upon the child’s development (Wallander and Varni, 1998). Thus in looking at outcomes of services for disabled children it is necessary to consider outcomes for both parents and child.

## 4.2 Summary of key issues and potential impacts on outcomes for disabled children and their families

The issues that emerged most strongly from the consultation as areas where improvement is needed were:

- Multi-agency working and key workers.
- Information for parents and professionals.
- Children's friendships and leisure.
- Substitute care, particularly after school and holiday provision.

Addressing some of these issues will contribute to disabled children's well-being in all outcome areas. Multi-agency working underlies ways in which services can improve children and families' lives in all outcome areas, and is the basis for many of the other improvements suggested in the consultation. Key workers are the front line for families of a well functioning multi-agency system, and research has shown that they are a central part of the support that parents of children with high levels of need require to alleviate stress and ensure that their children's needs are met. With the implementation of ESP, York now has a timely opportunity to develop a model of multi-agency working that supports a key worker service and extend this to families with children of all ages.

One of the key reasons for high levels of unmet need for disabled children and their families is a lack of information about what services are available to them. Again, meeting needs for information will contribute across all outcome areas.

Other areas of change identified in the consultation contribute more to some outcomes than others:

- Improving disabled children's access to friendship and leisure opportunities will impact on e*njoying and achieving* and is also an important part of emotional well-being so contributes to *being healthy.*

- Improving after school and holiday care facilities for disabled children will impact on *economic well-being* by enabling parents to participate in the labour market. It will also impact on children *enjoying and achieving* by providing more opportunities to spend time and take part in activities with other children; and on *staying safe*, if such facilities provide safe and appropriate care for children with specific needs, for example children with medical needs or autistic spectrum conditions.

- Improving equipment and housing adaptations services is central to many disabled children's *health and well-being,* to *staying safe* and to *enjoying and achieving.* Given the financial problems faced by some families in the current system for housing adaptations and their need to self-fund equipment because of inadequate budgets and delays in services, it can also contribute to the families' *economic well-being.*

- Involving children in decisions about service development and about their own care and treatment, and the development of outreach and community based services, such as Integrated Children's Centres, will contribute to outcomes concerned with *making a positive contribution.* Disabled children and their families are at increased risk of social exclusion so services which help them to make and maintain contacts in their own communities, and services such as support groups which help parents and children to make contact with others in similar situations, both contribute to *making a positive contribution.*

- For many disabled children, therapy services make a key contribution to *being healthy*, and speech and language therapy promotes children's communication skills so contributes to *enjoying and achieving.* As in most areas of the country, there are shortfalls in these services in York and any efforts to address these shortages, for example through reviewing the use of therapy assistants and joint funding to see whether there is scope for improvement here, could impact on these outcome areas.

## 4.3 Key recommendations

Recommendations arising from the consultation are described in Chapters 2 and 3. In this section, we highlight some actions that should be priorities for the Trust and identify some actions that could be achieved quite quickly – 'quick wins'. However, we would like to stress that although these are our suggestions for priorities, based on topics that received most emphasis in the consultation, all recommendations in Chapters 2 and 3 should also be considered by the Trust.

### 4.3.1 Priorities

*Multi-agency working*
Building on the enthusiasm for greater multi-agency working should be a priority for the Trust. An event to bring together all staff concerned with disabled children and their families to present findings of this and a number of other recent consultations and explain plans for taking these forward would be valued by staff. During our discussions with the task group we learnt of a number of initiatives that are already taking place and will address some of the concerns raised in the consultation. It appeared that most staff were not aware of these. An event of the type suggested would provide an opportunity to publicise to them the valuable work being undertaken under the auspices of the Trust.

Other priorities for multi-agency working should be:

- Instituting joint training for staff, possibly starting with training around the roles and responsibilities of all the different agencies who are in contact with families with disabled children.
- Developing partnerships with providers of sport and leisure services to increase access for disabled children to these facilities, and with housing services to address the problems surrounding housing adaptations.
- Setting up systems whereby better links with adult services are developed to smooth paths at transition.
- Looking at possibilities for a joint base for staff working with disabled children to meet - a Disability Resource Centre.
- Monitoring the implementation of ESP and planning for the extension of a key worker system to families with older children.

*Information*
An information directory for families with a disabled child should be drawn up in collaboration with parents. Both print and web-based versions should be produced and, with some additions of individual staff contact details, this could also form the basis of the information directory required by staff.

Creation of a Disability Resource Centre would also be a key factor in meeting families' information needs. Support groups for parents and young people could use the centre and the Trust, in collaboration with the voluntary sector, should identify ways of supporting the creation and maintenance of such groups.

*Family support and substitute care*
Inadequacies in after school and holiday care for disabled children should be addressed. Reviews of specialist childminder provision, out of school provision (particularly for 12-18 years olds), short term break provision for children with autistic spectrum conditions, and flexibility of school transport services would provide a sound base for decisions about improvements that are needed. Creation of out of

school clubs at Hob Moor Oaks and Applefields would be a valuable addition to facilities for after school care.

*Parent involvement*
We noted that the Trust's Involvement Group focuses on children's involvement. We recommend that systems for involving parents with disabled children in planning processes for the development of services should be a priority.

*Health and well-being*
York District Hospital and the PCT should review provision in A&E and in-patient services to meet the needs of children with autistic spectrum conditions or learning disabilities.

### 4.3.2 Quick wins

A number of issues arising from the consultation could be taken forward relatively quickly. We suggest that the following may fall into this category:

- Identify a *'champion'* to take forward plans for integrated services for disabled children and ensure that the needs of the children and their families are an important part of the broader agenda for multi-agency working.
- Hold a *'promotion event'* on plans for disabled children as described above.
- Produce an *information directory* for families and staff (as above).
- Facilitate Children's Trust support around *funding issues* for voluntary organisations, such as SNAPPY.
- *Parking*: revise criteria for the Blue Badge scheme to include children with behaviour and supervision needs; provide more disabled parking spaces outside council services; provide designated disabled parking spaces outside families' homes.
- *Housing*: suggest to the council that future planning applications should require a proportion of family-sized accessible housing.
- Review flexibility of *school transport.*
- Ensure that *parents' views* are taken into account as part of the Involvement Group.

As noted above, York is well placed to achieve greater integration of services for disabled children. This and other consultations that have recently been carried out provide a considerable amount of information on the positive aspects of services in York and what still needs to be achieved. We hope that the Trust will be able to take forward many of the recommendations from these pieces work. Finally, those who took part in the consultation wanted to know the results and we suggest that this report should be widely shared with both families and staff.

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# APPENDIX A

## Questionnaire for Service Providers

THE UNIVERSITY of York                                                        S | P | R | U

# Integrating Services for Disabled Children and Young People in the City of York: Consultancy Project for City of York's Children's Trust

# QUESTIONNAIRE FOR SERVICE PROVIDERS

This questionnaire is for service providers unable to attend the November workshops on services for disabled children, young people and their families living in the City of York. Please complete and return this to us by Friday 18th February 2005.

## 1. CONTACT DETAILS

You may complete this questionnaire individually or in a group. Please provide details below:

***Organisation/Agency***

**…………………………………………………………………………………………………**

***Main contact person***

Name ………………………………………………………………………………..……..

Job Title ……………………………………………………………………….…………

Tel ………………………………………………………………………………..……..

E-mail ………………………………………………………………………………………..

***Members of group completing questionnaire***
*(please tell us the roles or job titles of those involved)*

**……………………………………………………………………………………………………..**
**……………………………………………………………………………………………………..**
**……………………………………………………………………………………………………..**

**……………………………………………………………………………………………………..**

## 2. GOOD THINGS

**What do you think is good about services for disabled children and young people (or children with special needs) and their families in York…? *Please list up to three things.***

1.

2.

3.

## 3. GAPS OR PROBLEMS IN SERVICES

**At the workshops, service providers were asked to identify the sorts of things disabled children and their families should be able to do but cannot because of gaps or problems in services. Key gaps or problems identified are listed below. What, in your experience, are the gaps in York? Please tick all relevant boxes and then use the space opposite to tell us about any other gaps.**

### Key gaps/problems in services

☐ Sport and leisure opportunities

☐ Out of school activities, especially for children in special schools

☐ Short term care provision does not meet demand and not enough choice

☐ Childminding services

☐ Accessible public transport and support using public transport

☐ Lack of independent/supported housing

☐ Inaccessible public buildings

☐ Insufficient funding for housing adaptations

☐ Delays in the provision of basic specialist equipment

☐ Not enough transition support for young people aged 16 to 25 years

☐ Advocacy service

☐ Lack of financial support and advice

☐ Direct payments

☐ Meeting families' information needs

☐ No key worker service

☐ Training for parents on their child's condition and special needs

☐ Insufficient amounts of therapies

☐ Inpatient health provision for children with LD or ASD

☐ Specialist ICT assessments

☐ Emotional support for young people

☐ Practical and emotional support for parents

☐ Support for siblings

☐ Outreach support for families

☐ Social opportunities for young people and families

☐ Enabling parents to work

**Please list any other gaps or problems in services in the space below:**

*Please turn over*

## 4. AREAS FOR CHANGE

**Service providers were also asked what needs to change in the way services and/or agencies are organised in relation to both the way an individual service or agency is organised or delivered, and the way services or agencies work together. Key areas for change identified are listed below. What, in your experience, are the areas which need to change? Please tick all relevant boxes and then use the space underneath to tell us about any further areas for change.**

**Key areas for change**

☐ Creation of multi-disciplinary/multi-agency teams

☐ Provision of multi agency assessments

☐ Clearer interfaces within and across services/department

☐ Co-ordinated planning

☐ Co-ordinated appointments

☐ Joint funding

☐ Information about funding sources

☐ Secure funding of valued services

☐ Provision of key workers for families to coordinate services

☐ More specialist staff, eg community paediatricians, specialist therapists and Connexions workers

☐ Staff training and awareness, eg joint training across agencies, facilitation of learning more about each others roles

☐ Parity in service provision across age divisions

☐ Closer working with the voluntary sector

☐ Need for flexible services that are responsive to individual needs

☐ Earlier intervention needed, not purely crisis intervention

Please list any other areas for change in the space below:

**Thank you. Please return this questionnaire to the Social Policy Research Unit, University of York, Heslington, York YO10 5DD, in the pre-paid envelope provided by Friday 18th February 2005.**

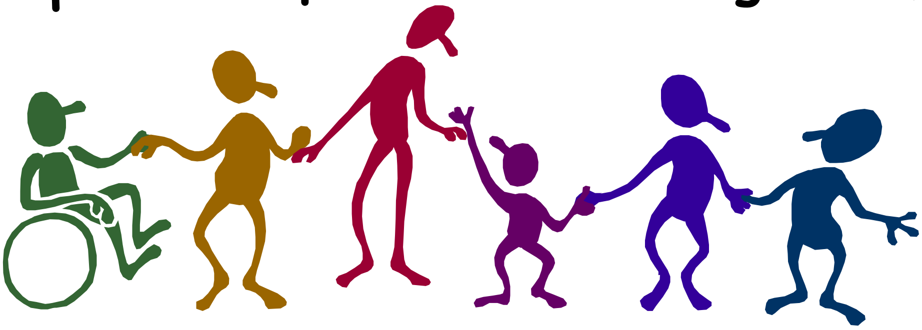
# APPENDIX B

# Questionnaire for Parents

THE UNIVERSITY of York

S|P|R|U

# Improving the lives of children and young people with special needs living in York



Dear Parent

City of York Children's Trust is responsible for developing and improving children's services in York. This Trust is a working partnership of health, education, social services, Connexions, and other services. The Trust wants to improve services for children with special needs. It has asked researchers at the University of York to find out what changes can be made to improve the lives and experiences of children and young people with special needs and their families living in York. The Trust is committed to responding to the findings of the consultation and will use the findings to develop and guide an agenda for change with regard to services for children with special needs.

THIS QUESTIONNAIRE GIVES YOU THE CHANCE TO HAVE YOUR SAY! TELL US WHAT YOU WANT FOR YOUR CHILD AND YOUR FAMILY.

Please return this questionnaire to us by Friday 4th March 2005. We look forward to hearing from you!

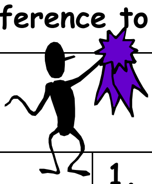
The Research Team
[Social Policy Research Unit, University of York]

PS. This questionnaire is only for families living within the City of York. If you live outside the city boundaries you do not need to complete it.

PPS. Your child's school has kindly offered to send this questionnaire out on our behalf. But please do not return your questionnaire to school. Please send it to us using the pre-paid envelope. Thank you!

## 1. Good things in your child's or family's life

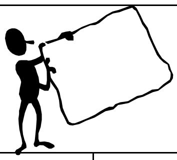
First of all, please tell us up to three good things in your child's and your family's life. **What do YOU value, what has made a positive difference to your lives…?**



| Good things for your child | Good things for you or other family members |
|---|---|
| 1. | 1. |
| 2. | 2. |
| 3. | 3. |

## 2. What you want for your child and your family

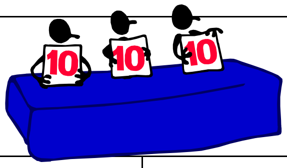
We have already met with a small number of parents and they have told us things they want for their child or their family. These include chances for their child to take part in sport and leisure activities; good, affordable out of school care; better parking facilities; and time out for parents and siblings. **What are the main things YOU want your child and your family to have, or to be able to do…?**



| Main things for your child | Main things for you or other family members |
|---|---|
| | |

## 3. What needs to change

How can services in York get better at meeting your child's or your family's needs…? Examples of things parents have already told us include better staff training on disability or special needs issues; easier access to benefits; a directory of services; and more social opportunities for children and families to meet up. **What do YOU think needs to change…?**



| **Ways services can be improved for your child** | **Ways services can be improved for you and other family members** |
|---|---|
| | |

## 4. Finding out what children think and feel.

As well as finding out what parents and professionals think, we are also finding out what children think and feel. Younger children are not used to filling in questionnaires so, instead, we are talking to them. Usually we talk to a child at home at a time convenient to the family. We use pictures and other activities to help children tell us what they think.

Do you think your child would like to tell us about the things they enjoy and the things they want to be able to do?

☐ Yes ☐ No

If you have ticked 'yes' please provide your contact details on the back page. We will then phone you to explain what is involved. You and your child can then decide if he or she is happy to take part.

## 5. What happens next?

After the Easter holidays we will be holding a meeting for parents to come to. At that meeting we will be finding out what parents think would be the best ways to improve services for children with special needs and their families. **Would you be interested in coming to that meeting…?**

☐ Yes, I would prefer a day-time meeting

☐ Yes, I would prefer the meeting to be in the evening

☐ No

## 6. Reporting back to parents

**Finally, would you like to receive a report of this consultation exercise…?**

☐ Yes ☐ No

## 7. Contact details

**If you have answered YES to question 4, 5 or 6 above, please provide your contact details below:**

**Name:** …………………………………………………………………………………….

**Address:** …………………………………………………………………………………….

…………………………………………………………………………………….

…………………………………………………………………………………….

**Postcode:** …………………………………………………………………………………….

**Phone:** …………………………………………………………………………………….

**Thank you very much for your help.**

**If you would like to speak to one of the researchers about this questionnaire, please phone Sue or Bryony on 01904 321950.**

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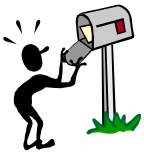
**Please return this questionnaire to the Social Policy Research Unit, University of York, Heslington, York YO10 5DD, in the pre-paid envelope provided by Friday 4th March 2005.**



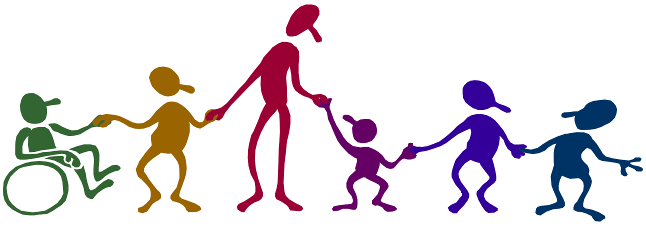
# APPENDIX C

# Questionnaire for Young People

THE UNIVERSITY *of York*

S|P|R|U

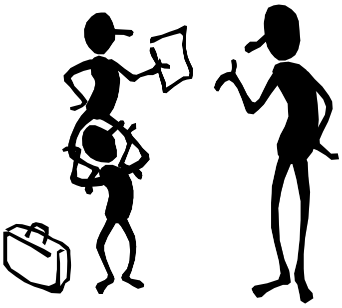
# How I want my life to be...



**Hello!**

Our names are Sue and Bryony.

We are doing some work for the people in charge of making sure that young people living in York have a chance to do the things they want to do.



They have asked us to find out what would make life better for children and young people living in York.

**What things do you want to be able to do?**

**What places do you want to go to?**

**What sorts of help do you want?**

We are asking lots of young people in York to fill in this questionnaire. It won't take long and we've given you an envelope for you to send it back to us. You don't even need a stamp!!

Thank you !

Sue and Bryony

PS. We work at the Social Policy Research Unit at the University of York. Please call us on 01904-321950 if you have any questions.

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## About you….

I am _____________ years. I am ….. a boy / a girl.

Which school/college do you go to? ______________________________________________

______________________________________________________________________________

# HOW WOULD YOU LIKE YOUR LIFE TO BE?

Here is a list of things that young people say they want to have or be able to do.
Put a tick in the RED BOX by all things in the list that **you already have or do**.
Next, put a tick in the GREEN BOX by all the things **you want to have or be able to do**.
Remember, you don't have to tick all the boxes.

### When I'm not at school

☐ Seeing school friends ☐
☐ Seeing other friends ☐
☐ Playing sport ☐
☐ Going to a club or activity ☐
☐ Doing things with my family ☐
☐ Meeting new people ☐
☐ Doing things at home ☐

### Needing help

☐ Doing things without my mum or dad having to help me ☐
☐ Going places without my mum or dad having to come too ☐
☐ Having money so I can pay someone to help me do the things I want to do ☐
☐ Getting about my house by myself ☐
☐ Using the toilet by myself ☐
☐ Having a bath by myself ☐
☐ Using the kitchen by myself ☐

### Getting out and about

☐ Someone to help me travel about ☐
☐ Using the bus by myself ☐
☐ Getting about outside by myself ☐

### Places to go

☐ Shops ☐
☐ Cafes ☐
☐ Leisure centres ☐
☐ Gyms ☐
☐ Swimming pool ☐
☐ Cinema ☐
☐ Park/sports field ☐
☐ Friends' houses ☐
☐ Library ☐

### When I'm upset or worried

☐ Being able to talk to my mum or dad ☐
☐ Being able to talk to friends ☐
☐ Having someone else I can talk to ☐

### Meetings about me

☐ Going to meetings about me ☐
☐ People listening to me ☐
☐ People asking me what I think ☐
☐ Knowing what the meeting is about ☐

### Leaving school

☐ Knowing what I can do when I leave school ☐
☐ Someone to help me plan for the future ☐

DON'T FORGET!!! Tick the **RED BOX** if you already have or do that thing, and tick the **GREEN BOX** if you want it. Remember, you don't have to tick all the boxes.

**This extra sheet is for you to write anything else you want to tell us about the things you want to be able to do. You don't have to write anything if you don't want to.**