

SCRUTINY COMMITTEE

TASK GROUP REPORT NO. 7

CHILDREN WITH SPECIAL NEEDS

JULY 2000

REPORT OF THE SCRUTINY TASK GROUP ON
CHILDREN WITH SPECIAL NEEDS

1. Membership of Group

The Task Group was made up of the following members: Cllr Brian Matthews (Chair), Cllr Mary Weber, Cllr Martin Elengorn, Cllr Pat Parsons, Cllr Angela Style. Meetings were also attended by the Chair of the Scrutiny Committee, Cllr David Cornwell. The Task Group was supported by Jo Potter, an external consultant.

2. Terms of Reference

The terms of reference received from the Scrutiny Committee suggested a general review of the delivery of services to Children with Special Needs and specifically highlighted the need to look at the effectiveness of the interface between Social Services and Education. The Task Group felt that it would not be possible to review all the services for children with special needs within the timeframe, and considered options for focussing the review.

Following discussion, it was agreed that the Task Group **'should review services for children with special needs with particular regard to the interface between Education and Social Services, between different sections within these departments and between the local authority and other statutory and voluntary organisations including Health'**.

3. Methodology

3.1 The Task Group met 11 times between February and July 2000. The following people submitted evidence:

Education

Jessica Saraga, Assistant Chief Education Officer
Barbara Owens, Special Educational Needs Team Member
Geraldine Herage, Education Officer, Social Inclusion
Janet Parsons, Chair of the Primary Head Teachers Forum and Head Teacher of Heathfield Primary School
Dave Talbot, Head Teacher of Orleans Park School
Anne Coward, Head Teacher of Clarendon School.

Social Services

Terry Earland, Head of Children and Family Services
Barbara Murray, Principal Social Work Manager
Mair Hutchings, Social Work Manager.

Health

Dr Anshasi, Community Paediatrician
Anna Brown, Chief Executive of Richmond Primary Care Group
Neil Roberts, Lead Commissioner for Children's Services at Kingston and Richmond Health Authority.

Voluntary Sector

George Mandow, Project for Children with Special Needs
Valerie Ivans, Project for Children with Special Needs
Anne Hollinger, Parent Partnership Worker.

Members

Cllr Tony Barnett, Chair of Social Services Committee
Cllr Brian Miller, Chair of Education Committee
Cllr Alison Cornish, Vice Chair of Education Committee.

- 3.2 The Task Group carried out a survey of parents of children with special needs using the Project for Children with Special Needs' database. The results of the survey are summarised in Section 7 and analysed in detail in Appendix 1.
- 3.3 The Group also received a number of internal and external documents, a list of which is attached at Appendix 2.
- 3.4 The Group visited the Project for Children with Special Needs based at the Croft Centre.
- 3.5 Contact was made with two other local authorities – Hertfordshire County Council and London Borough of Havering - to discuss alternative ways of structuring services.

4. Definitions

One of the first things the Task Group had to clarify was what was meant by 'children with special needs' since each agency has its own definition which differs to a greater or lesser extent from the definitions of other agencies.

Education

Education talk about children with 'special educational needs'. The 1996 Education Act says a child has special educational needs 'if he has a learning difficulty which calls for special educational provision to be made for him'. Within this group, children may have a range of different needs including Emotional and Behavioural Difficulties.

Social Services

Social Services have a duty to assess the needs of and provide services to ‘children with disabilities’ and ‘children *in need*’ and their families. This would include some, but not all, children with special educational needs and some, but not all, children with emotional and behavioural difficulties. This would also include a number of other children who do not necessarily fall within the Education definitions.

Health

The Task Group is not aware of a general definition used by Health, but the Community Paediatrician uses the World Health Organisation definition which talks about ‘children with any kind of impairment, disability or handicap which could be modified by medical, educational or social intervention’.

The Task Group decided to keep its own definition of children with special needs as broad as possible to encompass children with learning difficulties, physical disabilities, mental health problems, special educational needs (SEN) and emotional and behavioural difficulties (EBD). This coincides with the approach taken by the Project for Children with Special Needs who define it in the following way:

‘There is no exact agreed definition of Special Need. The term is used indiscriminately with disability, learning disability, learning difficulty, handicap etc. The Project uses ‘Special Need’ in a general way to include all needs from the extra help that a child may need at school to overcome a temporary learning difficulty through to multiple disabilities’.

5. Services for Children with Special Needs

5.1 Education

The aim of the LEA is to provide for as many children as possible in mainstream education through the use of classroom assistants or special units in schools. In addition there are three special schools in the Borough:

Strathmore (for children with severe learning difficulties)

Clarendon (for children with moderate learning difficulties)

Oldfield House (for children with emotional and behavioural difficulties).

In addition, a new Centre of Excellence has recently been established which combines the nursery in Windham Road with the Croft Centre.

Some children receive their education outside of the Borough – notably those with severe emotional and behavioural difficulties, profound and multiple disabilities and secondary autism. Plans are also underway to work jointly with Kingston, Merton, Sutton and Croydon to develop a shared facility for girls with emotional and behavioural difficulties. A multi-agency day care facility is also being developed jointly with the Royal Borough of Kingston upon Thames Social Services, South

West London Community Trust and Kingston and Richmond Health Authority to provide a day service for children with mental health difficulties.

Whilst the Task Group was carrying out its work, it was also aware that the Education Department were carrying out a review of services for children with Emotional and Behavioural Difficulties.

The Educational Psychologists have an important role in working with children with special needs, and the Education Welfare Service can, in some cases, also get involved.

5.2 Social Services

Social work support can be delivered either through the Locality Teams or one of the specialist teams depending on the nature of the referral. Specialist services offered by Children and Family Services include: residential respite care; foster respite care; befrienders; family link; domiciliary care; a family support worker; Crofters after school club; sponsorship to a specialist childminder or sponsorship to specialist pre-school provision. Many of these services are based at the Croft Centre which also houses the Children with Disabilities Team.

5.3 Health

The Health Service provides a range of services which deal with children with special needs. These include GPs, Health Visitors, the Community Paediatrician, Clinical Child Psychology Department, Child and Adolescent Mental Health Service, Speech and Language Therapy Service, Occupational Therapy, Physiotherapy and The Maple Unit which is a residential respite unit for children with disabilities.

5.4 Voluntary Sector

There are a number of voluntary organisations working in this area, some of which receive substantial funding from the local authority. These include:

The Project for Children with Special Needs which provides information and support comprising a directory of services, newsletters and a help-line; a counselling service for children and their families; a sitting service; promotion of leisure facilities; and a toy library. The Project is based at the Croft Centre.

The Parent Partnership which is part of the Project for Children with Special Needs and provides information and support to parents of children with special educational needs. This includes a telephone help-line, appointments and home visits, development of parent friendly information on SEN and facilitation of focus groups with parents to enable consultation over their perceptions of the service. The Parent Partnership is also based at the Croft Centre.

There are a number of other voluntary organisations in the borough including Crossroads, Home Start and Off the Record and a number of parents groups, many of which also meet at the Croft Centre.

6. Examples of Good Practice

The Task Group was impressed by the efforts professionals are making across all agencies to work together and to try to build links between the different elements of what is a complex and ever-changing structure. Representatives of all the agencies interviewed were aware of the difficulties parents must have in understanding the structure and in navigating their way around it. There was a willingness to build relationships and to work well together and considerable effort is put into this to make the whole thing work.

There are also some very good examples of 'cross boundary working'. These include the following:

- The Speech and Language Unit at Heathfield Primary School (funded jointly by Health and Education) is seen as a good example of Health and Education working together.
- The Statutory and Voluntary sectors worked together and consulted with parents over the need for the re-establishment of the post of Specialist Health visitor in the Richmond PCG area. The Project for Children with Special Needs consider this to be a model for future consultation.
- The Project for Children with Special Needs holds Toy Library days where a range of therapists and social workers are also on hand to give advice.
- Social Services have recently drawn up a joint protocol with Health and Education for funding out of borough placements for children with disabilities.
- Social Services, Health and Education have recently been working together to draw up a joint assessment pro-forma for children with disabilities to avoid the need for parents to fill out separate forms.

However, the group concluded that despite these efforts, the system remains complex and difficult to understand and the evidence gathered from all quarters indicates a need to simplify and clarify it further.

7. Survey of Parents

A survey of 360 parents on the Project for Children with Special Needs' database was carried out during the month of May. A response rate of 20% was achieved. The detailed analysis is attached as Appendix 1.

The results of the survey can be summarised as follows:

Communication between agencies

31% thought that communication between the agencies was good, 40% thought that it was neither good nor bad and 29% said that it was bad.

There were some complimentary comments about some of the services provided and about individual professionals some parents have dealt with. However, the majority of the comments received made suggestions for improving the interface between services and the following are examples of these.

‘As a parent I have had to become my child’s own key worker in order to ensure that services are co-ordinated and appropriate. This is often due to poor linking and communication.’

‘It’s not about breakdown in communications – the various agencies don’t really understand the concept of joined up working. We have been pushed from pillar to post and back. God help children who come from disadvantaged backgrounds whose parents are not familiar or confident in negotiating the system, however well intentioned they may be’.

Repeating information

51% of parents said that they got fed up with repeating information and 49% said they did not.

The following comments from parents give a flavour of what those who commented said.

‘There should be scope for getting the agencies together initially after the child is diagnosed. Then for parents there might be a clearer path to follow rather than lots of fragmented advice’

‘There needs to be one person who has all the details of the child who co-ordinates with all the agencies e.g. a Specialist Health Visitor’

‘Set up a central database then all the repetitive paperwork can be printed out and checked and updated rather than filling in forms over and over’.

8. Findings

The Group concluded that despite the best efforts of the agencies involved, the system facing a parent of a child with special needs remains difficult to understand and to negotiate. This is particularly so for parents who are less articulate and, for whatever reason, less able to act as their child’s own ‘key worker’. The key findings of the Task Group are listed below together with proposals for future action.

8.1 Relationships

Findings

Generally professionals think that relationships between agencies are good although this appears to be down to individual relationships rather than systems or procedures. The Task Group welcomes the recent decision to retain a separate Joint Action Group for Children with Disabilities as a means of enhancing interagency working.

Education staff highlighted the lack of a protocol for schools to contact Health in the same way as one exists for them to contact Social Services. Equally some Health staff appear to be unclear in some respects as to which meetings with Education/Social Services they need to attend.

Although protocols exist for Social Services' involvement in cases concerning physical or sexual abuse, no such protocols exist in cases of emotional or behavioural problems.

The voluntary sector (specifically the Project for Children with Special Needs and the Parent Partnership) feel that they are not kept sufficiently informed by the statutory agencies and that there are inadequate procedures to ensure that communication takes place if individual relationships between professionals break down.

Way Forward

The respective roles of each agency, their involvement in individual cases and how they communicate with each other needs clarification. Specifically this needs to involve clarification of roles and responsibilities, the need for additional protocols, clarification of which meetings each agency needs to attend and communication with voluntary organisations.

The process of excluding a child from school and the agencies that need to be involved also needs to be reviewed. It is important, in most cases, including all permanent and many short term exclusions, to involve Social Services and all agencies involved with the child (such as Youth and Community Services) at an early stage, when consideration is being given to excluding a child from school.

The Task Group would also like to see closer working between the voluntary agencies (such as the Parent Partnership and Project for Children with Special Needs) and schools. One solution might be for representatives from these voluntary agencies to attend occasional meetings of Head Teachers forums to discuss issues of common interest.

8.2 Health Service Structure

Findings

Both professionals and parents are confused by the structure of the Health Service and there is some evidence that Health Service staff themselves are confused by a complex structure that is in a constant state of flux. Officers from the Local Authority report particular concerns about establishing lines of accountability within the Health Service.

This may contribute to the concerns that both parents and professionals have expressed about communication within Health and the length of time for referrals and appointments to be made.

The confusion over the structure is not helped by the lack of co-terminosity between health and local authority boundaries.

Way Forward

Efforts need to be made to clarify the structure for both the professionals working in the field and also for parents who have to navigate their way around the system.

The issue of co-terminosity also needs to be given serious consideration as health service boundaries are reviewed over the next few years.

8.3 Length of Time Taken to Produce Statements of Special Educational Need

Findings

The LEA's performance in this area was highlighted by the District Auditor as only 50% of statements are produced within the target of 18 weeks (although this is not atypical amongst LEAs). Action is currently being taken by the LEA to address this issue. However, the length of time taken to get health appointments or to get reports back from health professionals remains a contributory factor.

Way Forward

Further action needs to be taken to reduce the time it takes to produce a Statement of Special Educational Need. This needs to include closer co-operation between agencies to reduce the time it takes to get health appointments and to get reports back from health professionals.

8.4 Budgeting and Planning for Children with Special Needs

Findings

The three main statutory agencies have different definitions of special needs and different priorities. This together with constraints on budgets can make agreement on allocation of funds difficult. A recent Department of Health circular 'Leadership for Health' proposes pooling of budgets between PCGs, Health Trusts and Local Authorities to make services more integrated and 'patient friendly'. 'Leadership for Health' also suggests that agencies need to consider the transfer of funds and functions to one agency which would allow it to provide a seamless service.

Way Forward

The feasibility of developing a more co-ordinated approach to budgeting and service provision in this area along the lines mooted by the Department of Health needs to be investigated.

8.5 Structure

Findings

The Task Group was aware of discussions at national level about possibly moving some social services responsibilities into health.

Consideration was also given to whether a restructuring of Education and Social Services would enhance co-ordination. Contact was made with the London Borough of Havering where Education and Children's Social Services were merged over a year ago resulting in a new department called 'Children and Lifelong Learning'. However,

a recent Social Services Inspectorate report on Havering was very critical of the arrangements and the authority is considering the future of the new department.

Contact was also made with Hertfordshire County Council who are also reviewing their services with a view to setting up a new Children, Schools and Families Department and a new Adult Services Department which would have a special relationship with Health.

Way Forward

Following the experiences of the London Borough of Havering, the Task Group were of the view that a restructuring of Education and Social Services is not necessarily the solution to problems which are essentially about processes, communication, sharing information and creating a level playing field for children and their parents. However, the Task Group does wish to see closer working between Social Services, Education and Health along the lines suggested in 8.4 above.

8.6 Shared Information

Findings

Information on children is not shared between the agencies which means that time is wasted at appointments with professionals on form filling and going over old ground. In the Education Department there are difficulties with computer systems (Education Welfare depends largely on paper records) which means that it is not possible to track a child within the department. The Task Group acknowledges the need to ensure confidentiality of some information, but is still of the opinion that the majority of information can be shared between agencies.

Kingston and Richmond Health Authority have recently been successful in getting funding to develop a project called 'Electronic Records Development and Implementation Programme' (ERDIP). This is a two year project, the aim of which is to develop electronic records for all maternity patients and children aged under five. These would be accessed by Health and Social Services, but would not, in its initial stages, involve Education.

Way Forward

This will be a good starting point in developing a common database and the Council needs to work closely with the project. However, on its own, it will form only part of the picture for children with special needs. Efforts therefore need to be made to ensure that ERDIP is ultimately expanded to include children aged over five years and to allow the system to be accessed by Education.

8.7 Child Centred Approach

Findings

The results of the survey indicate the level of frustration felt by many parents as they have to take their child around to the various professionals for diagnosis, consultation and advice.

The voluntary sector, school heads and many parents argue for more of a child centred or one stop shop approach where the relevant professionals get together with the parents and child to provide services rather than the parent and child having to go from pillar to post seeing various professionals, few of whom seem to share information or talk to each other.

Social Services, Education and Health are currently piloting joint assessments of children with disabilities but this excludes a large number of children with special needs (including those with emotional and behavioural difficulties and autism).

Although the services provided at the Croft Centre are a very good example of interagency working, there are problems of accessibility for children who live on the Middlesex side of the Borough. In this context the Task Group was pleased to hear that a new Development Worker post has recently been established in the Project for Children with Special Needs, the role of which will include outreach work in schools.

Way Forward

The Task Group supports the efforts being made towards the development of joint assessments and would like to see these expanded to embrace children with other types of special need including emotional and behavioural difficulties and autism.

The Task Group would like to see the outreach work in schools done by the Project for Children with Special Needs and the Parent Partnership developed further so that they can give advice and information to parents who are not able to get to the Croft Centre. In the longer term, the Group would like to see a facility like the Croft Centre developed on the Middlesex side of the Borough.

8.8 Referral Procedures

Findings

Head Teachers mention the difficulties they and parents experience when referrals are made between one service and another.

Additionally, the Task Group originally received the impression that although Health refer all children with special needs to Education as soon as they are diagnosed, the Education Department takes no action until a parent writes to them. However, the Education Department advise that they do take action straight away on some referrals, such as where a child has a sensory impairment. In other cases (e.g. where a parent is concerned about a child's lack of progress), they will wait until a parent or school contacts them.

This can be confusing for parents, many of whom assume that action is automatically taken on the referral from Health. There have also been cases where health visitors have advised parents that action will be taken automatically by Education on referral by Health.

Way Forward

The procedures for making referrals between one agency and another need to be clarified for both parents and professionals and thereafter monitored closely.

8.9 Level Playing Field

Findings

In both the meeting with heads and the survey of parents, a strong message came across about the inequality of access to provision. Parents have to play a major role in lobbying for services for their children and finding their way around the system. Children whose parents are more articulate and knowledgeable stand a far greater chance (it seems) of accessing services for their children than children whose parents are less able. Many parents argue for a key worker for all children who would help explain the services available and how to access them.

The Task Group were pleased to hear that the Richmond PCG have prioritised and identified funding to reinstate the role of specialist Health Visitor that had previously been cut (the Teddington, Twickenham and The Hamptons PCG already have such a post).

Way Forward

All children with special needs should have access to a key worker who would help to explain the services available and how to access them. There are a number of options for providing this including the Specialist Health Visitors and other professionals from Health, Social Services or Education.

The Parent Partnership Worker plays a role in enabling parents of children with Special Educational Needs to access the services they need. However there is evidence of a need for an additional resource based either with the Parent Partnership or more generally with the Project for Children with Special Needs to provide information and help to parents.

The respective roles of the Key Workers and Parent Partnership/Project for Children with Special Needs workers would need to be clarified and co-ordinated to make best use of the resources.

8.10 Resources in Schools

Findings

Some schools place a very large proportion of children on their Special Needs Register. For example, at one primary school a third of the children are on the Special Needs Register. Only a very small number of children from each school can be sent to the Education Psychologist for assessment every term. This leads to unacceptable delays – particularly for schools with large numbers of children with special needs.

Some parents have commented that too much responsibility is delegated to schools who do not have the expertise or resources to deal with many aspects of special needs.

Head Teachers have commented on the need for more resources to do preventative work with children and families (where there is no likelihood of a statement) at an early stage in their school career to prevent problems occurring at a later stage. The Task Group was pleased to hear that resources allocated to the Behaviour Support Team have recently been increased to help schools carry out this work.

Way Forward

The Task Group would like to see:

- The allocation of more Education Psychologist hours to schools for a defined period to help clear the delays that have built up.
- Provision of training and support to teachers in schools on the different types of special needs
- A review of the additional resources provided to the Behavioural Support Team to assess the effectiveness of any preventative work carried out.

8.11 Consultation and Communication with Children and Parents

Findings

The statutory agencies vary in the extent to which they consult with service users. Education have a number of processes for consultation with specific groups of parents. Services for Children and Families have consulted parents and carers in the past and the Quality Protects Management Action Plan now includes a policy for ongoing consultation with service users. The Kingston and Richmond Health Authority canvass the views of users and carers as part of service development, but do not have a systematic process for finding out service users' views.

The Project for Children with Special Needs reports that although consultation has improved recently (e.g. over the re-introduction of the Specialist Health Visitors), it could still be improved further.

Service providers from all agencies need to be able to place themselves in the shoes of the service receivers rather than restricting their thinking to the narrow confines of their own service and existing budgets.

Way Forward

Consultation processes need to be further developed by all the agencies involved and particular consideration needs to be given to the development of systematic processes for discovering the experiences of service users.

9. Recommendations

The following recommendations are divided into categories since some of them are general recommendations relating to two or more of the agencies, some relate to specific council departments and some are recommendations to other agencies (Health and the Voluntary Sector).

GENERAL RECOMMENDATIONS

It is recommended that:

9.1 Children with special needs be allocated a key worker who would provide detailed information about the full range of services available and would enable parents to access these services. The statutory agencies should decide between them how this is provided in each case. (see Section 8.9)

9.2 A more co-ordinated approach to planning and budgeting for services for children with special needs be developed by the statutory agencies following the proposals put forward in 'Leadership for Health'. (see Section 8.4)

9.3 Social Services work closely with Kingston and Richmond Health Authority on developing a common database for children aged under five and that this database be expanded as soon as possible to include children aged over five and to be accessible to other agencies such as Education. (see Section 8.6)

9.4 Social Services, Education and Health and voluntary bodies review the processes required to improve the interface between agencies including the way referrals are made. (see Sections 8.1 and 8.8)

9.5 The concept of joint assessment for children with disabilities be developed by the statutory agencies and extended to cover all children with special needs including those with emotional and behavioural difficulties and autism. (see Section 8.7)

9.6 Systematic consultation with service users be further developed by all the agencies and that joint consultation be carried out where appropriate. (see Section 8.11)

9.7 Further action be taken by Education and Health to reduce the delays in producing statements of Special Educational Need. (see Section 8.3)

EDUCATION

It is recommended that:

9.8 Additional Education Psychologist hours be allocated to schools for a limited period of time to help reduce the build-up of SEN assessments in some schools. (see Section 8.10)

9.9 The effectiveness of the additional resources allocated to the Behaviour Support Team be reviewed to see whether they have helped to improve preventative work in schools. (see Section 8.10)

9.10 Additional training and support to be provided to schools on the various types of special need they may need to deal with. (see Section 8.10)

HEALTH

It is recommended that:

9.11 The various arms of the Health Service (health trusts, PCGs etc) operating within the Borough clarify their structure and responsibilities for both the professionals working in the field and for parents. (see Section 8.2)

VOLUNTARY SECTOR

It is recommended that:

9.12 The Project for Children with Special Needs and the Parent Partnership worker develop closer links with schools and extend the outreach work they do through schools. (see Section 8.7)

APPENDIX 2

LIST OF DOCUMENTS RECEIVED BY THE CHILDREN WITH SPECIAL NEEDS TASK GROUP

- Parent Partnership Service: Occasional Paper No 1 ‘A Joint Endeavour’
- Project for Children with Special Needs: ‘A Guide to Services in Richmond upon Thames for Children and Young People with Special Needs’
- Parents of Children with Autism: ‘A Centre of Excellence for Children with Autism in the London Borough of Richmond’

- London Borough of Richmond upon Thames: ‘Review of provision for pupils with emotional and behavioural difficulties at Key Stages 1 and 2.’
- London Borough of Richmond upon Thames: Special Educational Needs Policy’
- Best Value Performance Indicators for SEN
- Education Welfare Service Annual Report
- Portage Service Consumer Survey
- Business Management reports for Education Psychological Service and Peripatetic Classroom Assistant Service

- Council for Disabled Children: Review of planning arrangements for young people with disabilities/special educational needs – report for London Borough of Richmond upon Thames
- Services for Children and Families: Review of Respite Care Services for Children with Disabilities
- London Borough of Richmond upon Thames, Social Services: Child Care Policy
- London Borough of Richmond upon Thames: Child Protection Guidelines for Day Care Staff

- LGA Briefing on Special Educational Needs and Disability Rights in the Education Bill
- Annexe B Special Educational Needs of the Consultation Paper on the proposed provisions in the Education Bill
- Department of Health Circular: ‘Leadership in Health’
- Department of Health Circular: ‘Planning for health and health care incorporating guidance for health and local authorities on health improvement programmes, service and financial frameworks, joint investment plans and primary care investment plans’

CHILDREN WITH SPECIAL NEEDS TASK GROUP

SURVEY OF CHILDREN WITH SPECIAL NEEDS

OVERVIEW OF SURVEY RESULTS

1. Sample Size

Questionnaires were sent to 360 families on the Project for Children with Special Needs database. 69 families replied resulting in a response rate of almost 20%. Of those who replied, 63 live in the London Borough of Richmond and the remainder live in neighbouring boroughs.

2. Age Groups

The sample appears to give us a reasonable distribution of age groups with 32% in the 8-11 age group, 27% aged 5-7, 20% aged 12-16, 18% aged under 5 and 3% aged over 16.

3. Nature of Special Need

The respondents appear to be heavily weighted towards those with a learning disability of some type although it has to be said that categorisation of special need was difficult with many children having a multiple disability. Categorisation has been done on the basis of the major disability or the one mentioned first.

The largest group of children are those with Autism/Aspergers (28%) followed by those whose special need has been termed 'Learning Difficulty' (16%).

4. Schools

Of those who answered the question (63), the largest proportion (27%) attended a Richmond primary school, followed by 20% attending an independent school and 15% attending a state school outside of the Borough. The vast majority had had experience of dealing with the Education Service – particularly the Special Education Services and the Education Psychologist.

5. Social Services

Far fewer families had had experience of dealing with Social Services than either Health or Education. The largest group (30%) had had experience of 'Social Work support', whilst 19% had experience of the Crofters Club and 25% of the Befrienders Service.

6. Health

The vast majority had had experience of the Health Service in some way with 92% saying that they had dealt with a GP, 72% with the Speech and Language Therapy Service, 65% with the Community Paediatrician and 61% with a Health Visitor.

7. Voluntary Sector

54% of respondents say that they have experience of dealing with the Project for Children with Special Needs including the Parent Partnership Officer. The other voluntary agencies most mentioned were Crossroads and IPSEA.

8. Communication

31% of respondents said that they thought communication between the agencies involved with their child was good, 40% said that it was neither good nor bad and 29% said that it was bad.

A number of parents have taken the trouble to comment further and some of these comments are very enlightening. A small sample of quotations are repeated here.

Questionnaire 67 *'I would like the person who delegates my school's request out of their own area to another to take responsibility for seeing that it is then actually acted on. It would be appreciated if these people would respond with responsibility and care rather than a 'jobsworth' passing onit is very difficult to keep asking.'*

Questionnaire 63 *'We have professional experience as a social worker and NHS manager and the backing from social workers available to us as adoptive parents. Without this we would have got nowhere.....we get fed up with professionals failing to manage basic administrative processes and continually wanting to assess rather than offer practical help. In our experience, it is only easy to access practical help if you can afford the private sector.....The culture isn't there and the local policies aren't there to support Government policies about special needs education, social exclusion, partnership In Education, far too much is devolved to school level and the school is then at sea if you have special needs that are at all unusual.....It's not about breakdown in communications – the various agencies don't really understand the concept of joined up working. We have been pushed from pillar to post and back. God help children who come from disadvantaged backgrounds whose parents are not familiar or confident in negotiating the system, however well motivated they may be.'*

Questionnaire 49 *'The Education Department, when a statement was disagreed with sent a 'see you in court' letter rather than attempting any form of mediation. This is not only bad policy, wasteful of the Borough solicitor's time, but also extremely damaging for both the child and the family.'*

Questionnaire 66 *'As a parent, I have had to become my child's own key worker in order to ensure that services are co-ordinated and appropriate. This is often due to poor linking and communication. Communication, particularly in Health between*

clinicians and the people making funding decisions (ie PCGs) is appalling. There is none. I appear to be the only vehicle.

9. Repeating Information

51% of parents said that they got fed up with repeating information to the different agencies and 49% said they did not.

Comments from parents included:

Questionnaire 33 *'Every time you meet another person, you spend most of the appointment going over the same information about your child and then spend time telling them what we are doing. I do not feel I have had any concrete support from any agency. (We need) one person to co-ordinate for your child with a one stop appointment – Psychologists, doctors, Parent Support worker, Information etc, not weeks of traipsing from one person to the next. A fast link parent support as soon as diagnosis is given not 6 weeks after'*

Questionnaire 7 *'There needs to be one person who has all the details of the child who co-ordinates with all the agencies eg a specialist Health Visitor'*

Questionnaire 24 *'a directory of services for children with Autism would help'*

Questionnaire 26 *'Set up a central database then all the repetitive paperwork can be printed out and checked and updated rather than filling in forms over and over again.'*

Questionnaire 27 *'there should be scope for getting the agencies together initially after the child is diagnosed. Then for parents there might be a clearer path to follow rather than lots of fragmented advice.'*

Questionnaire 28 *'Things have improved since the Croft Centre was established but agencies still need to stop being protective of their empires.'*

Questionnaire 41 *'It would be helpful to have a panel meeting of all those dealing with the child's problems periodically or to have a central bank of records detailing aspects of the child's special needs and available to all parties'*

Questionnaire 42 *'all assessment and no practical help. When child is initially assessed you get lots of attention and then a resounding silence! If resources are short train the parents how to help. Thank God for the Project and support groups.'*

Questionnaire 54 *'I have never once had the pleasure of talking to a health professional who had read/discussed what another professional has said. Briefing always has to be from me the parent. I tell each of the experts what the other one has said.....school based services seem to read each others reports but I'm not sure they consult each other or look for a comprehensive picture – feel they are operating in a vacuum'*

Questionnaire 56 *'Suggestion for improvement: Identify and keep a record of all children with speech and language problems. Track them and support them in schools. Employ specialist team who have interest and expertise in Aspergers'.*

Questionnaire 60 *'I think Speech and Language Therapy should be funded by Education since it is vital to a child's education'*

Questionnaire 61 *'Unwillingness to give diagnosis – constant referrals up the chain with professionals being unwilling to give an opinion. Because of this we contacted professionals privately who gave an opinion straight away.'*

Questionnaire 69 *'as a parent group called 'Together' we presented a paper advocating a centre of excellence for children with autism of which the Project has a copy – our suggestions for improvements between agencies are outlined in this.'*

Analysis of Comments from Questionnaires

Survey respondents were asked to comment particularly on problems they had experienced with communication between agencies and on types of information they got fed up with repeating.

Communication

29 respondents commented on the communication between agencies. Problems were identified between Health, Social Services and Education. Problems were also identified within Health with some confusion within the Health Service as to where patients should be referred.

Some comments were also made about the length of time it can take to get referrals between services and the length of time it takes to get a statement (9 months in one case).

Individual comments were made about specific services which are not reported here.

However, there was considerable consensus between the respondents on the following issues:

- **Parents have to chase up all the agencies and act as their child's 'key worker'. If they do not take the responsibility for chasing and arranging services, their child loses out.**
- **Consequently there is considerable inequality between those whose parents are articulate and 'in the know' and those whose parents are not.**
- **There is a lack of information about what services are available for children with different sorts of special needs. A number of parents say that they wish they had found out about specific services much sooner since they feel their child lost out.**
- **Parents suggest the need for someone to coordinate the services available and to act as a child's key worker. Others suggest the need for planning meetings between the agencies – particularly after diagnosis to map out what services are available and how they would benefit. Some suggest the need for better information about what is available.**

Repeated Information

21 respondents commented on the information they particularly get fed up with repeating.

Most respondents said that they had to repeat their child's medical history – their birth, diagnosis and prognosis and any treatment they had received. One person said that they had to repeat this information to 10 professionals. More than one parent commented that they spend much of the time in their health appointments going over

old ground which leaves very little time for active support. It was also commented that the help offered was often in the form of yet more diagnosis when what was needed was practical help.

Many parents commented that a central database of information on the child was needed which could be accessed and updated by all the agencies involved.