

1st Draft

Evaluation of how SSE is meeting the needs of families with Disabled Children.

Introduction.

KIDS is a local charity working with families with disabled children and children with special needs covering the Sure Start Euston area, we were approached by SSE to carry out an evaluation to assess how they are meeting the needs of families with Disabled Children and children with special needs i.e. those whose development is causing concern. SSE states that a child under four years of age has a disability or special needs if she or he:

- Is experiencing significant developmental delays, in one or more of the areas of cognitive development, physical development, communication development, social or emotional development and adaptive development; or
- Has a condition, which has a high probability of resulting in developmental delay.

We looked at the aims of Sure Start specifically regarding families with disabled children or children with special needs and formulated questions to encourage the appropriate information. We visited and interviewed families with a disabled child or child with special needs, known to have received the SSE Home Learning Service through KIDS. We visited all the SSE drop-ins and interviewed at least one worker from each and a broad spectrum of relevant workers in the SSE area. Below is a bar chart of all people interviewed for this evaluation.

The evaluation was carried out from January 2004 to April 2004.

The Aims of SSE

“Sure Start aims to transform life chances of young children, particularly those with special needs and disabilities who live in areas of disadvantage. Programmes are specifically concerned with reaching all families within the catchment area. To achieve Sure Start targets efforts must be made to ensure that services are designed to meet the particular needs of individual families so that they feel welcomed and supported.”

“Sure Start is committed to promoting the inclusion of children with special needs or disabilities within all of its services. Programmes must ensure that all Sure Start buildings allow easy access to families who have members with disabilities.”

(paragraphs 1.1 and 1.6 of Sure Start supporting families who have children with special needs and disabilities booklet)

Sure Start Euston the area:

SSE covers Regents Park, St Pancras and Somerstown wards, in an area between Euston Road and Camden Town Tube Station.

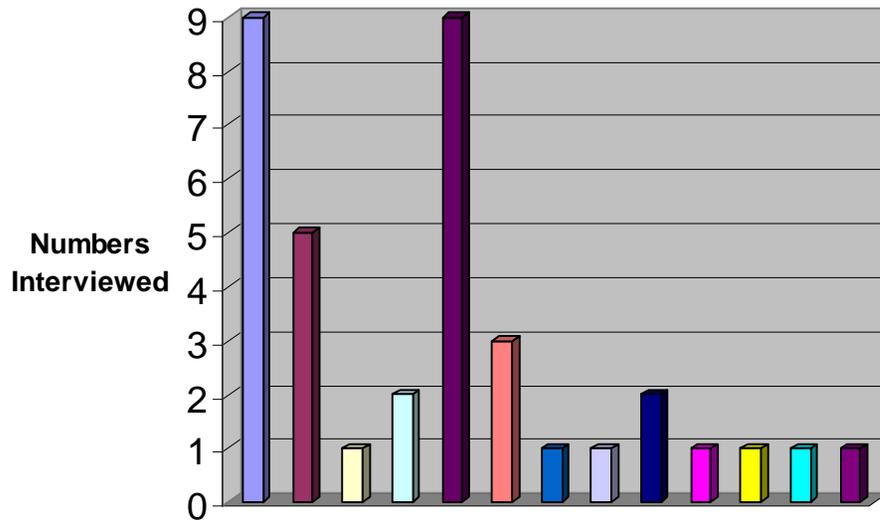
Enclose map

Our method:

We gathered our information by interviewing the following people:

- **9 Families with a Disabled Child or a Child with Special Needs who had received or were receiving Home Learning and were living in the SSE area**
- **5 SSE Drop-ins**
- **1 SSE Outreach Librarian**
- **2 Parent Forum Chairs**
- **9 SSE Parent Support Workers**
- **3 KIDS Family Project Workers**
- **1 SSE/KIDS Home Learning Worker**
- **1 Specialist Health Visitor**
- **2 Social Workers from Camden's Disabled Children's Team**
- **1 SSE Clinical Psychologist**
- **1 SSE Deputy manager-Community Involvement**
- **1 SSE Deputy Manager-Family Support**

People Interviewed

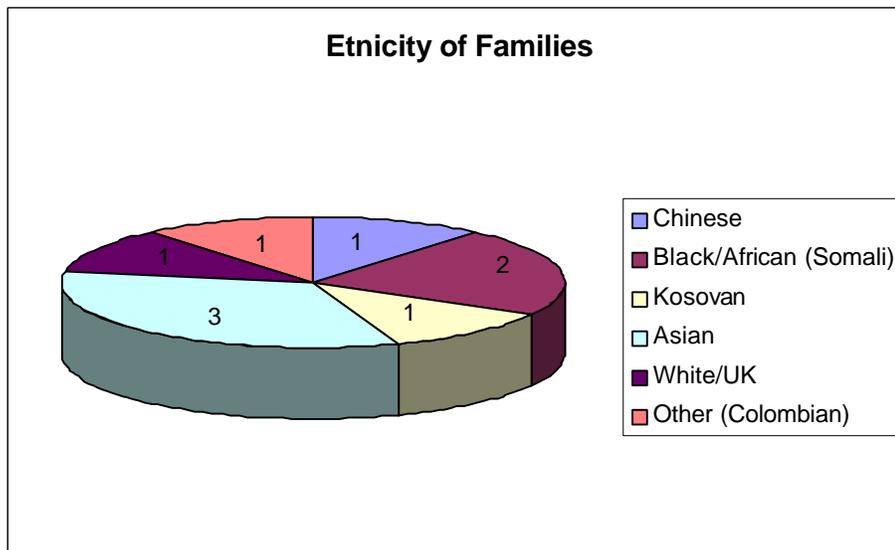


- Families with a Disabled Child or a Child with Special needs
- Drop-ins in SSE area
- Outreach Librarian
- Parent Forum Chairs
- SSE Parent Support Workers
- KIDS Family Project Workers
- SSE/KIDS Home Learning Workers
- Specialist Health Visitor
- Social Workers from Camden's Disabled Children's Team
- SSE Homestart Volunteer Coordinator
- SSE Clinical Psychologist
- SSE Deputy Manager-Community Involvement
- SSE Deputy Manager-Family Support

Our Aims

- To find out how families have benefited from services
- To find out how many families of those interviewed use other SSE services
- To find out what families thought of the services
- To find out how SSE endeavour to reach families with disabled children or children with special needs
- To find out how accessible families found centres
- To find out what would make services more accessible
- To find out what obstacles were encountered in making services accessible to families
- To find out what support and training would be helpful to workers to enable them to make services more accessible and to meet the “particular needs of families”
- To find out if workers have access to sufficient information about what support and resources are available to families with children with disabilities or special needs
- To find out families’ views of Sure Start
- To find out families found out about SSE services
- To find out what other services families would like

Ethnicity of families



- 1 Chinese
- 2 Black African
- 1 Kosovan
- 1 Asian (Kashmir)
- 2 Asian (Bangladeshi)
- 1 Colombian
- 1 White/British

Ages

All children were under four when they received a service.

Total number of children who have received SSE Home Learning Service : 18

Parents' Responses

Parents found out about SSE services from the following sources:

- By post
- Health Centre
- Specialist Health Visitor (CDT)
- SSE Parent Support Worker
- Greenland Rd Children's Centre
- Physiotherapist
- Families in Focus
- Phone call from SSE
- Don't remember

Families were asked if SSE services had been of benefit to them and if so, how?

Families were unanimously positive in response to this question. Listed below is a quote from each family.

-“Yes definitely, I was new to the area.... the Home Visitor introduced me to people and showed me what was available”

-“I have learnt from....(the Home Learning worker).., she brought lots of toys for my son”

-“Yes!...(the Home Learning worker)... helped my child, she really helped him with counting, colours, singing and play!”

-“Useful” helped with learning and play, (Home Learning)

-“Very useful”, with DLA and Statement of needs, (Home Visitor)

-“Yes, of course, I didn’t know which toys were suitable for...Home learning helped me with that.”

-“...(the Home Visitor)... helped with forms,”... phone calls, liasing with professionals, nursery applications and SSE trips.

-“Yes”..... information re: drop-ins and trips through the post.

-“Yesa learning opportunity for my son” and help with charity applications.

Parents were asked:

On a scale of 1-10, 1 being poor and 10 being excellent, how they rated the services according to the list below.

The response relates generally to SSE services and was very positive, see chart below:

Welcoming	10	8	7	9	10	10	7/8	6	7/8
Accessible	10	8	7	10	10	10	8	10	9
Reliable	10	8	7	9	10	10	9/10	10	6/7
Useful for child	10	8	7	10	10	10	7	10	8/9
Useful for you	10	8	7	10	10	10	8	5/6	8/9

When asked if they would have liked another service this is what families said:

- More information in Somali
- No
- “Yes”, respite for shopping”
- More storytelling, including on Saturdays
- Respite for my disabled son
- Respite/crèche/play centre for siblings when parents need to attend appointments
- Parenting groups
- Drop-in specifically for babies under 12 months
- Spoken English classes

Parents were asked which other SSE services they knew about:

- 4 said Home Visitors
- 5 said trips
- 1 said none
- 5 said Drop-ins
- 1 said Hopscotch Drop-in
- 1 said Library sessions
- 1 said ESOL course
- 1 said Computer course

When asked which other SSE services they had used parents replied:

(Number in brackets denotes where more than one parent had this response)

- Somali Home Visitor (2)
- Trips (3)
- Library sessions
- Home Visitor (4)
- Drop-Ins (4)
- SSE Party
- None (3)

Those who replied “none” said that they were:

- Too busy
- Their English wasn’t good enough
- They didn’t know about them

Those who had used other services, when asked how they were, replied:

Trips

- “The whole family loved it”
- Older siblings were not allowed so difficult during half terms
- 2nd carer to push wheelchair or buggy was not allowed-2 carers are needed when one child is in a wheelchair and another in a buggy
- “They were very good”
- “They were very cheap”

Library sessions

- “Very good....children love them”

Drop-Ins

- Helpful when baby was younger for meeting people

Parent Support Workers

- “They were very helpful”
- “kind people”

When families were asked to specify what was good about the services they replied:

(Number in brackets denotes where more than one parent expressed this opinion)

- provides useful information (2)
- access to books and videos
- storytelling
- it's free (2)
- a chance to see new places
- easy, local pick up points
- a chance to meet other parents/people (2)
- a chance for my child to mix with other children (3)
- play
- lots of toys
- helpful and friendly
- good to get children out
- children's enjoyment

Families said that services could be improved by:

- having leaflets in Somali
- don't know (3)
- nothing
- could be bigger (drop-in)
- entrance needs to be bigger (drop-in)
- separate baby and toddler groups
- more frequency (library sessions)
- allow siblings to come on trips, maybe for a small extra cost
- allow a second carer on trips for families with more than one buggy or wheelchair
- library space needs to be bigger, can be crowded
- more computers in libraries
- would prefer crèches to drop-ins

When we asked the parents "What is your overall impression of Sure Start?" they replied as follows:

- "very good, especially for people with English as a Second Language"
- informative about local activities
- "valuable"
- have recommended to friends
- "very good idea, there wasn't much there before"
- "very helpful"
- "good for mums and kids"

- “OK”
- “good”

When asked if there had been opportunities to be involved in the development and running of Sure Start services, parents said:

- yes, attended meetings for 8 weeks at Greenland Rd
- no (5)
- yes, (letters and leaflets) didn't take up (2)
- yes, attended 2 meetings at Parents Forum, my English wasn't good enough at that time.

Parents other comments were:

- would like opportunity to learn computer skills and use the computer regularly
- Would have liked a Home Visitor sooner after sending my form
- Would have liked more information about nurseries, schools and playgroups
- Better quality English teachers
- “Thanks for all SSE has done!”
- Where do I get Sure Start information if I move?
- None (4)
- More activities in half term, to include siblings

Parent Forum Chair Responses

Two Parent Forum chairs were interviewed and asked about the representation of parents with disabled children on their committees and attendance at events, neither had any parents of disabled children on their committees nor were they aware of that any disabled children attended their events, apart from one child with a medical condition.

In order to encourage parents of disabled children/disabled parents to attend the forum and forum events, one forum advertised that families with special needs were welcome and that it is up to the family to make their child's needs known, whilst the other did nothing actively.

When planning outings and events, one forum chair said that they took into consideration the needs of disabled children/disabled parents by ensuring that there was physical access/ramps, wheelchair accessible doors and toilets at all the venues they used. They also employed a specialist crèche worker if they knew beforehand that disabled children

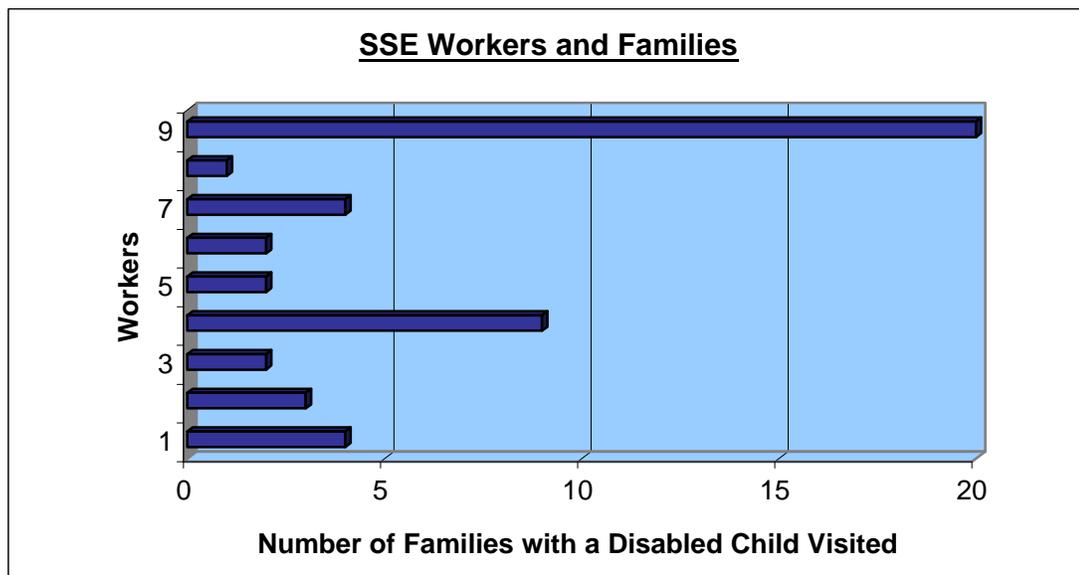
would be attending. Also they asked the Parent Support staff to encourage the parents to come.

The other forum didn't at this stage take into consideration the needs of disabled children.

Parents Support Team Responses

The parent support team have worked with over 40 families with a disabled child/special needs in the last three years, covering a wide range of disabilities (including Autism, global delay, speech and language delay and developmental delay). All the team have worked with at least one family with a disabled child see chart below. They have also worked with number of disabled parents 2 with hearing impairments 1 with learning difficulties and a disabled grandmother.

These families came from a wide range of ethnic communities.



The type of support the families required as assessed initially by the Parent Support Workers ranged from:

- Emotional support for the parent either around the child or other emotional issues e.g. one parent was very angry and unable to engage in any of the services offered, another parent was in denial about her child's diagnosis and did not attend appointments. Other parents had their own mental health issues
- Children's needs; the families needed help in securing nursery placements, accessing drop-ins, support through statementing

process, help for the child to develop their social and language skills and confidence, support in developing their child's skills and support with their child's behaviour one family needed help in recognising that their child had behaviour difficulty and not that they were "naughty". Overall assessment to ascertain the degree of delay or a diagnosis

- Housing, families had a range of housing needs from overcrowding to being housed inappropriately on the 20th floor with an autistic child unaware of danger.
- Access to other services, families needed help in accessing and using other services for their child; information about local support, support with parenting capacity, generally getting out of the house and getting to services. One parent new to the country needed initial support to go out and information about where to go. This was particularly important for those families where English was a second language.
- Other parents needed physical help to go to the park, attend drop-ins or just to have a break from their children.
- Benefits advice and grants some parents were not getting the correct benefits and others needed help to raise extra money for things like toys and equipment and household essentials.

The team referred families to a wide range of services in the statutory, voluntary sector as well as Sure Start local services. These included: the Child Development Team, Social Services, Education, Housing vulnerability panel, Welfare Rights, Debt counselling, KIDS, Family Service Unit, Sure Start Euston services such as other Parent Support Workers, Psychologist, Speech and Language Therapist, Drop-ins, Parent Forum events, classes such as ESOL computing, parenting groups, Strengthening Families courses, Home Learning Service and others.

The degree to which parents were able to take up these services varied, with some families able to attend all the services and some unable to engage in any. The team did not generally feel that the parents consistently attended the Drop-ins for different reasons, some only attended when they were accompanied by a worker or volunteer others were able to attend if the drop-in was specifically for their ethnic community, others found that the demands of their children prevented them from interacting with the other parents. However nursery places on the whole were taken up. Some families needed a lot of input from their Parent support worker before they could begin to use new services. Not many services, it was felt, were able to meet the needs of parents with learning difficulties or other disabilities. Some parents did attend the

events, but not generally the coach outings; one parent attended an event without her disabled child. The language used to describe some services was considered responsible for the slow take up.

The needs of the families as identified by the Parent support team were that they were:

- Isolated with no support network from family or friends
- Isolated because they were new to the country or the area
- Cultural issues; language barriers, cultural acceptance of disability,
- The vast number of appointments the family may have gets in the way of using services. Physically getting to appointments is difficult.
- Parents were stressed and physically exhausted.
- Routine life chaotic
- A number of parents had their own physical or mental health issues. Some mothers appeared particularly depressed
- Low self esteem
- Unable to accept their child's disability.
- Not accessing mainstream services as well as they could, the effort-required means that they may not bother, as they may not get a service any way.
- Parents feeling overwhelmed.
- Emotional needs – reassurance that they are managing their child.
- Home situation relationship difficulties/single parent.
- Not able to take up services.
- Parents' needs for parenting themselves.

The team felt that there was evidence of good practice and the following were indicators of what worked well:

- When all disabled services including KIDS were in at the right time.
- Fulltime nursery places allocated which enabled the parent to look at their own needs.
- Workers portage trained.
- When home visitors helped parents to get to appointments.
- When appointments were organised on the same day one after the other, this was helped by the health worker on the team having direct access to the Primary Care Trust and the Child Development team.
- Parents helped to establish routines.
- Multi-agency working together both within the team and with external agencies.
- Holistic family approach- all the needs of the family were looked at.

- When the workers knew about the appointments and understood the outcomes, so that they could offer support to the family.
- Workers accompanying families to appointments
- Multi-agency assessments carried out at the child's nursery.
- When parents able to use parenting groups.
- During one off events workers have been able to collect families and support them to get to the event.
- An organised package of support for the family.
- Training and groups building up self esteem of the parents.
- Referral system to KIDS and the Psychology service works well no real waiting lists.
- Feel welcomed at Drop-ins

Difficulties encountered and what didn't work.

- Attitudes, parents feeling uncomfortable at Drop-ins and events
- Cultural barriers to taking up services
- Difficulties in finding out who does what and where to turn.
- Lack of support groups for parents at assessment stage
- Criteria for service and criteria cut-offs.
- Ending of Home based learning.
- Working with only one parent whilst, other parent not engaging
- Poor communication from GP's
- Lack of knowledge about resources.
- Cuts in 1:1 support
- Funding, lack of money resource changes not always clear-cut
- Transition into school parents need more contact not less.
- Housing applications and process complicated.

The team had received some feedback about the different services parents were using and had their own thoughts about these services.

- Generally services were good, well received and parents were very grateful.
- Some changes were needed at the Drop-ins
- The Home learning service was working extremely well but not automatically identified as a Sure Start Euston Service?
- Multi-agency workers within the team working well the rest of the team using the worker with the expertise on disability for information and advice. There was good feedback about the psychology service.
- Parents not always clear about what services they do need.

- Good links now established with housing for families with disabled children but less so with the Disabled Children's team or adult team working with disabled parents.
- Contact with Child Development team is good; particularly the Specialist Health Visitor and Health Visitors in general have been very helpful and useful.
- Mixed feedback about Child Development Team from parents.
- Some parents see improvements in their child as coming from the child rather than as a direct result of the intervention of services.

The team were asked if they had adequate information about services for families with a disabled child/Special needs.

- Some of the team felt that they had adequate information.
- Others would use the team member with the expertise in disability /special needs.
- Special needs not always considered
- When the child's diagnosis is not clear and does not fit into the defined criteria, some of the team were unclear as to what support was available and where to seek help for those children. They did not automatically think of KIDS for support.

All the team knew about the Home Learning service but not all had made referrals to it. All disabled children were passed on to the team member with expertise in disability who would refer to the Home Learning Service. Generally the team felt that there was not enough involvement of the Home learning service with the Sure Start team and not enough referring back into the team for Sure Start Services e.g. if the family needs support around housing.

5 Drop-In workers' and 1 Outreach Librarian's Responses

All the Drop-in Workers and the Outreach Librarian recalled their services being used at some time by Disabled Children or Children with Special Needs. Workers from each service recalled numbers as follows:

- Approximately 4 over the past 3 years
- Approximately 3 in total
- 2 currently, maybe more
- A few
- Occasional
- 5 (1 single Somali father attended with son with Autism)

We asked the workers how they had tried to make their services more accessible to Disabled Children and Children with Special Needs and their families and/or Disabled Parents, notably 1 Drop-In was full accessible. They replied:

- We are currently looking at the accessibility of the library
- We use tactile and interactive books and stories with props
- I give out SSE information at baby clinics
- The Drop-in is fully accessible
- Our newsletters welcome everybody
- The Outreach Worker does Home Visits
- We work alongside other professionals working within the premises, i.e. Social Services
- We publicise the Drop-in through other services
- Everybody is welcome, disabled, non-disabled, all ethnicities (3)
- Sure Start recommend us
- We are friendly and approachable
- Other parents are very supportive
- Have offered assistance to parents on stairs
- Accessible WC downstairs and quite spacious WC upstairs (in Drop-in)
- Would plan play accordingly if needed by family
- Provide advice around play to encourage development
- “We would try to change if we had Disabled families”
- we use talking books and toys to encourage speech
- Have referred 2 Autistic Children to KIDS
- Positive aspects of Drop-Ins i.e. Social skills; play skills and encouraging Speech, Language and other areas of development

Workers had encountered some obstacles in trying to make their services more accessible, most significantly that one Drop-in was up a long flight of quite narrow stairs, and 2 other Drop-Ins also had some stairs at the entrance. The following are obstacles workers had encountered:

- Stairs into Drop-In (3)
- Stair lift not working
- “Asian families don’t come because they prefer to go to Hopscotch”
- “Somali families prefer to go to the Somali Drop-In”
- WC’s are not accessible (2)
- The building is not very safe or accessible-there is a step and narrow doorways
- No ramp
- Language difficulties

- Speech and Language Therapist doesn't attend Drop-Ins
- Cultural barriers-some families feel that their child's disability is "God punishing them".

Workers reported that they try to reach families with a Disabled Child or a Child with Special Needs through the SSE Home Visitors but also in the following ways:

- Through other organisations i.e. baby clinics and drop-Ins
- Will be setting a specific time in the library to welcome any families
- We have publicised the accessibility of our building through SSE Home Visitors
- We do our best to welcome people
- People can talk to an Outreach Worker if they have any problems
- Outreach Worker does Home Visits to SSE families
- Word of Mouth
- If we were aware of any family we would ask the SSE Home Visitor to bring them in
- "We don't exclude anyone"
- 2 Soft Play sessions per week
- Accessible WC's will be fitted soon
- We have highchairs
- Other families have been encouraged to bring new families

Workers were asked how families with Disabled children and Children with Special Needs and/or Disabled parents had benefited from attending Drop-Ins or Library Sessions. Children's development in the area of Socialization was most frequently cited as well as support for parents around specific issues such as nursery applications. These are the workers responses:

- Social Skills for children (4)
- Children have gone on to playgroup within the same premises (now closed)
- Children have been referred on to Speech and Language Therapy
- Soft Play (2)
- Good informal network for finding nursery places
- Advice and support around issues such as potty training and nursery applications (3)
- Enjoyment
- Supports and encourages development

- Integration/inclusion of families with a Disabled child is of benefit to all families, they become more understanding and learn to see the individual
- Books, stories
- Parents can socialize and learn from each other (2)
- Everybody is welcome
- Comfortable non stigmatising environment

Most workers said that they would like more information about types of support and resources available for families with a disabled child although some said that they knew where to find the information if and when they needed it:

- 1 would like to be on a mailing list to ensure access to all relevant information
- 1 felt she received and passed on information as much as she could
- 2 said they would research more if they were working with a family with a Disabled child
- 2 would like more information for parents and workers

All workers would like further training or support regarding working with families with Disabled Children or Children with Special Needs. 2 workers are currently working towards an NVQ 3. 2 workers said that they had no specifically related training. Workers had several suggestions for training that might enable them to support families better.

- Disability awareness Training
- Play activities and how to adapt to different needs (2)
- Coping with difficult behaviour (2)
- Communication skills
- Annual Training Day
- Child Protection
- Health and Safety
- First Aid
- Guidance around specific disabilities
- Manual Handling
- Risk Assessments
- Makaton
- Talks and information on Disability and how to detect earlier
- Talks for parents and workers from a Psychologist to help prepare them
- Home Learning for all parents of a disabled Child

Other comments were made regarding issues that had come up for workers. Some Somali families had not been properly informed or there had been language difficulties when information regarding their child's disability was given. 1 worker felt that professionals needed to ensure that families had fully understood the information.

Discussion with other professionals with Sure Start Euston

Generally there had not been much contact with either disabled children or disabled parents.

On how well Sure Start Euston met the needs of families with a disabled child one felt it was difficult to tell as within the family support side very little raised about the families with disabled children and that within case reviews and supervision there was a real opportunity to raise the profile of the needs of these families. However, within community involvement it was felt that the needs were being met by ensuring that there was but there was room for improvement.

KIDS Workers and Specialist Health Visitor Responses

We interviewed 3 KIDS Family Project Workers, 1 KIDS/SSE Home Learning Worker and 1 Specialist Health Visitor from Greenland Road Children's Centre. 4 out of 5 have or are currently working with children in the SSE area.

The workers have referred families to the following SSE services. The number in brackets denotes where more than 1 worker has referred to this service.

- Home Learning
- Home Visitor
- Drop-Ins (2)
- Safety Equipment Loans
- SSE money for toys
- SSE money for a baby group
- Recommended contacting SSE
- Father's Project
- Outings
- Somali Drop-In
- None

Workers said that families didn't always take up services, once referred, but were more likely to use the Drop-Ins if someone took them there. Families mostly did take up the Home Learning Service. These are the reasons workers gave for families not taking up services:

- Language difficulties (2)
- Parent in a state of denial regarding child's disability
- Cultural factors, some families prefer not to go out (2)
- Some families don't have a good understanding of what services are and so don't know if they are helpful
- Families would like a worker to take them there (2)
- Families need a known person to be there
- Families are not in the SSE area
- Some parents are reluctant to go locally because they don't want their community to know about their difficulties

Workers were asked if they had received any feedback from families who had taken up services. Families value and develop good rapport with home based workers. Workers who had feedback from families reported the following:

- Home Learning Workers are good at developing rapport with families
- Home Learning Workers are a good consistent link with families
- Families seem to value service at home
- Families liked the Drop-In and saw this as a good opportunity for children to learn social skills through play with others i.e. queuing for the slide
- 1 family had complained that the Home Visitor had not been able to help with re-housing

4 out of 5 workers inform families of Sure Start services available if they have a child under 4, regardless of disability.

When asked they have or are working with families living in the SSE area 4 out of 5 said yes. They worked with the following numbers of families:

- 8-12
- 3
- 2
- 1
- None

Workers would like easy to access information about Sure Start Services available. We asked them if they had enough information about the services available to them:

- No, but would research if necessary (2)
- Some but would like easy, accessible information i.e. e-mail or mailing list (2)
- No, I need more, I would like a map of all Sure Start services in Camden
- Small, easy to carry leaflets would be useful

Workers overall impressions of Sure Start Services were generally that it was a “good idea” but that there was a greater need for services to link together. Workers said:

- It’s a good idea
- It can be overwhelming, everybody gets involved with the same family, when another gets no one
- There are lots of services, but there is no ‘gluing force’
- It’s a good idea because it starts when mum is pregnant
- It would be better if it were done in a more pro-active way, there is a need to build bridges to access all areas of the community
- All services (including inside the home) should be structured according to the cultural differences of the families
- It’s a good idea to help new mums
- The outings sound good
- ‘a bit bitty’ it would be easier for workers if services were borough wide
- Families with multiple difficulties need a key worker to support and liase

Camden’s Disabled Children’s Team

Two Social Workers from the Disabled Children’s team covering the Sure Start Euston area were contacted. They reported that the DCT were unclear about numbers of Disabled Children SSE were working with. 1 Social Worker said that none of the families in her caseload were currently using SSE services.

Recommendations from Parents Interviewed

- Parents have expressed a need for more information in other languages widely used in the area. (e.g. Somali).
- A need to extend current services suggestions included: more storytelling sessions; more respite; parenting groups; spoken English classes; more computers in libraries; separate baby groups.
- A need to reach families not accessing services because of language barriers.
- A need to be more flexible and look at individual needs of families i.e. allowing a second carer on trips when necessary.
- A need for activities or provisions, which can include siblings during school holidays.
- A need to look at accessibility of premises.

Recommendations from the Parent Forum Chairs interviewed

Both the forum chairs were very open to change and had lots of suggestions on what would help.

- Information on disability /special needs
- Advice about little changes that could be made that would make the forum and the events more inclusive
- To raise awareness about disability at the forum.
- As there is so much to take in setting up a forum, it would be helpful to have an induction pack with guidance on what needed to be considered when organising events
- To actively recruit a parent with a disabled child to be a committee member.
- Activities/events to be planned to include all needs.
- Introduction to disability/special needs on what language to use and ideas for basic activities.
- Helpful if Parent Support Workers (without breaching confidentiality) would advise the forum in advance of parents that may attend and for them to actively encourage parents to come.
- If parent forum members were more aware of the needs of families with disabled children then they could be more supportive to them at events etc.

Recommendations from Parent Support Workers

- Generally how to improve the child by knowing how to help
- Recognising all disabilities and the criteria for disability clearly defined. Picking up those children currently falling through the net e.g. those children with mild developmental delay and sensory impairments.
- Team overall to gain more experience and understanding about disability particularly the impact upon the family.
- Better and earlier identification of children with special needs/disability and is SURE start EUSTON reaching them all. Quicker assessments and fast tracking families into services.
- Access to disability awareness training and other relevant training.
- Overcoming the fear of not getting it right with parents and ability to say I don't know.
- Specific parenting groups.
- Groups for parents of disabled children with a view to inclusion into main stream services when they are ready
- Review of drop-ins how to make them more welcoming and open to families with a disabled child. Structure to drop-ins to include behaviour and developmental sessions.
- Training around special needs for drop-in workers. Assessments checklists for workers
- Meeting the needs of parents with learning difficulties
- Disability services may put parents off when the child on the boarder line or not yet diagnosed
- More assistance to attend appointments and transport to attend events. lives of families with a disabled

Recommendations from Drop-In Workers and Outreach Librarian

- There is a need for all premises to be accessible.
- A need to ensure that families from all communities are being reached.
- A need for Speech and Language Therapist to attend Drop-Ins.
- Most workers said they would like more information, both for workers and for parents.
- All workers would like further training (see list in Drop-In responses).
- A need to ensure families have fully understood information given to them.

Recommendations from other Sure Start Euston Professionals

- Disability awareness training.
- Behaviour management training.
- Better links with health visitors as they are key to identification.
- Building bridges with health services improving relationship and sharing of knowledge and expertise.
- Utilizing the expertise within the team.
- Learning about child development.
- Ongoing training not one offs at the induction stage.
- Ensuring that the needs of families from ethnic minorities are met and enabling families to gain full support and understanding of their child's needs. This may be why DNA's are high within ethnic communities.
- Develop better links with the home learning worker
- Home learning worker to have more active role in linking families into Sure Start Services.
- Better networking with other professionals working with families with disabled children.

Recommendations from KIDS Workers and Specialist Health Visitor

- Families are more likely to use Drop-Ins if someone takes them or if there is a known person there.
- A need to overcome Language difficulties.
- Workers would like easy to access information about Sure Start services.
- A need to access all areas of the community.
- Services structured according to cultural differences of the families.
- A need for families to have a key worker

Recommendations from contact with Camden's Disabled Children's Team

- A need for DCT to have a stronger link with SSE services.
- A need for DCT to have more information regarding SSE.

Conclusion

Families were unanimously positive about SSE home based services, however there was some evidence that not all families were linking into SSE's mainstream services. The reasons for the poor take up of mainstream services were complex and involved both language and cultural issues and those connected to having a disabled child. Not all services are currently physically accessible to all Disabled Children or Disabled Parents but there was a recognition that changes needed to be made and in some cases were already in process. Some services and events need to take into account the needs of Disabled Children/Parents and develop a more welcoming policy.

Since the start of SSE the team have worked with over 30 families with a disabled child or a child with special needs. It is difficult to ascertain whether this is a true reflection of the actual numbers within the Sure Start local area, as it is well documented that it is difficult to collate statistics on numbers of disabled children. However the Specialist Health Visitor is currently working with 9-12 families in the area.

There was a notable absence of parent representatives with Disabled Children on the parent forums.

Amongst the SSE workers there was a range of levels of expertise and knowledge about the impact of disability but workers from the SSE team were able to draw on the knowledge SSE Parent Support Worker(KIDS).

There was an awareness that overall the profile of Disabled Children/children with Special Needs needed to be raised and there was strong commitment from all those interviewed to make changes and to develop more inclusive services.

Key to abbreviations:

SSE : Sure Start Euston

DCT: Disabled Children's Team

CDT: Child Development Team