

A Better Start: Children and Families with Special Needs and Disabilities in Sure Start Local Programmes

by Anne Pinney¹

Sure Start Local Programmes (SSLPs) supported children under 4 and their families by integrating early education, childcare, health care and family support services in disadvantaged areas. Providing services to families where there were special needs and disabilities was one of the core tasks that the programmes were required to carry out. This study looked at how they tackled it.

Key findings

- ▶ SSLPs varied in the ways they identified and counted special needs and disabilities, but those studied estimated that they were working with between 5 and 120 children in this category, with an average of 40, or 5% of the age group.
- ▶ The highest incidence of need reported by SSLPs was speech delay, followed by behaviour issues, autistic spectrum disorders, development delay, hearing or visual impairment and Downs syndrome.
- ▶ It was the way SSLPs improved the services they offered to *all* families - providing more of them, in more accessible, better settings, with more flexible responses to what parents wanted – that made it possible for families with additional needs to participate.
- ▶ Where SSLPs provided services targeted at children with special needs and disabilities - like Portage and special playgroups – they were more likely to reach children with more complex needs. The SSLPs that were doing this were in contact with larger numbers of families in this category.
- ▶ Family Support services proved the most useful aspect of Sure Start for families with children with more complex needs. These services help families to cope in crises, obtain services and benefits, gain skills and confidence in supporting their child's development and get some respite from their caring responsibilities. Home-visiting was particularly important in reaching isolated and vulnerable families.
- ▶ The availability of specialist health services like speech and language therapy and mental health outreach was significant for these young children, enabling preventive work to occur, and developing parents' skills in promoting their child's development and managing their behaviour.
- ▶ Inclusive practice, flexible staffing and funding have made early learning, play and childcare opportunities available for children with special needs and disabilities, but early years provision was not always well integrated with other SSLP services.
- ▶ Future improvements to early years provision will need to be made in developing the links between services that enable forward planning and supported transitions for children with special needs and disabilities, that develop staff skills and confidence and enable holistic responses to children's needs.

¹ The author is an independent researcher who was commissioned to carry out this study by the National Evaluation of Sure Start (NESS), at the Institute for the Study of Children, Families and Social Issues, Birkbeck College, University of London.

Background

Sure Start Local Programmes – now Sure Start Children’s Centres- were community-based and supported an average of between 400 and 800 children under four years old. There were 524 programmes which were rolled out in six stages or ‘rounds’. The National Evaluation of Sure Start (NESS) has been assessing the impact, implementation, community characteristics and cost effectiveness of SSLPs by examining the first 260 programmes, the first four rounds.

Although allowed scope in the design of the programme, all SSLPs were expected to provide core services: outreach and home visiting, family support, good quality play, learning and childcare, health care and advice, and support for children and parents with special needs.

There was considerable evidence about the barriers that parents of disabled children encounter. They face extra financial costs, are less likely to be able to work, and the majority live on a low income. These families are under stress, both from the demands of their child and from difficulties of obtaining support. They are often in contact with a wide range of professionals and report ‘a constant battle’ to find out what is available and the role of different agencies. Black and minority ethnic families, in particular, tend not to take up the services and benefits that are available. There has been concern about how far disabled children and those with Special Education Needs (SEN) are able to access early learning, play and childcare. And the support available for pre-school children with SEN has been poorer than that available for those at school, though there is clearly potential for preventative work when children are younger.

Reforms intended to tackle these weaknesses were underway alongside Sure Start Local Programmes, and were outlined in the *Children Act 2004* and the *National Service Framework for Children*. Initiatives like *Together from the Start*

(2003), which provides guidance for improving identification, intervention and multi-agency support for families; the *Early Support Programme*, which develops good practice in these areas; and reports on offering opportunities, like *Improving the Life Chances of Disabled Children*, all provided a climate in which SSLPs could make a contribution. The emphasis in all of them was on early intervention, greater coordination between services and improving the skills of the workforce.

Aims of the Study

This research project aimed to explore:

- how SSLPs developed services to meet the needs of children and families with special needs and disabilities in terms of core (mainstream) and specialist (targeted) provision;
- the range of practice across different areas and for different groups;
- factors which enabled some SSLPs to excel in meeting the needs of children and families with special needs and disabilities, or which acted as barriers to progress.

The definition of special needs and disabilities used is that contained in the *Sure Start guidance (2002)*:

“A child under four years of age has a disability or special needs if she or he:

(i) 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

(ii) has a condition which has a high probability of resulting in developmental delay.”

Methodology

The research for this study was carried out in 2005-6. It was conducted in two stages.

Stage One:

- Literature review, interviews with national stakeholders, review of evidence from NESS, web searches and pilot field work in three SSLPs.

Stage Two:

- Fieldwork in a sample of twelve SSLPs (by this time most were Sure Start Children's Centres), selected from a shortlist of 50. The list was based primarily on evidence from NESS, showing the extent of special provision offered (national survey, implementation), spending on SEN (cost effectiveness) and ratings of SSLPs in terms of multi-agency teamwork, access to specialist services, strategies for identifying users and other key characteristics (programme variability). The twelve study areas were representative in terms of socio-economic and BME profile based on NESS local context data and covered a range of lead partners, regions and area type. Field visits involved:

- a review of literature and information for parents;
- interviews with programme manager, heads of services or special needs, and a variety of staff;
- semi-structured discussions with parents;
- short questionnaires on key services and special needs numbers;
- phone interviews with partner organisations and board members.

Findings

Approaches to Special Needs

SSLPs varied in the profile they gave to special needs in policies, literature and imagery. This tended to be higher when the programme manager or senior staff had personal or

professional experience of special needs and disabilities. The parents of children with special needs highlighted this as an area for improvement.

Improving the Profile: recommendations from parents

- Programmes need to ensure that the profile of disability is raised at all forums, meetings and events and that there is representation from parents;
- Planning of services and events needs to take into account the needs of disabled children and parents and to be welcoming for them;
- The accessibility of premises and events needs to be reviewed in terms of physical access and attitudes, with the needs of individual families taken into account;
- All imagery associated with the programme should reflect diversity in a positive way;
- Everyone working in the programme or centre should have an inclusive attitude and all staff should be responsible for inclusion within their own roles.

Specialist Expertise

SSLPs also varied as to whether they employed a staff member with expertise in special needs or disabilities. Half employed such a worker, usually in the outreach team, who made home visits to children and families with significant and complex needs, and worked with them on activities to promote development and to establish routines. Workers enabled families to access relevant services, activities and benefits; planned and supported children and parents in transitions to early years settings; and advised colleagues on special needs, reviewing cases with them and providing training to all programme staff and volunteers. In several areas these staff also ran targeted groups for children with special needs.

In several programmes, the special needs expert was a key staff member using their experience to influence broader SSLP practice – including staff development opportunities, information systems and funding arrangements. These SSLPs were amongst the most effective in working with children and families with special needs and disabilities. Almost half the SSLPs visited had no staff member playing a lead role in relation to children and families with special needs and disabilities. Those that had a programme manager and/or family support manager who took a keen interest in special needs and disabilities were nonetheless working well with this group. But in the few SSLPs which had no in-house special needs/disability expert and seemingly, little senior management interest, staff were notably less confident in describing their work with this group and appeared to be working with few, if any, children with significant and complex needs.

Targeted Services

SSLPs also varied in the amount of special or targeted services they offered. Over half ran these services, either with a developmental focus or giving parents and children the chance to 'stay and play' in a supported environment. Parents were enthusiastic about the opportunities given by special groups and play opportunities to share experiences.

"Lauren's starting to notice for herself that she's different from the other kids, so I think it is important for her to be around other kids with special needs...Even though we may treat them all the same...they do need that something extra," one parent explained.

Some SSLPs expressed concern about specialist provision, feeling that fully inclusive services met the needs of families and that targeted provision was liable to be stigmatised. But these programmes were less successful in reaching families with children with disabilities or more

complex needs. One quarter of the SSLPs visited said that they had worked with few, if any children with significant and complex needs and did not think they had a clear role in doing so, since there were specialist statutory and voluntary agencies to help these families. But every SSLP was responding to the wider group of children with special needs, which includes those with moderate delays and difficulties, like speech and language delay and behavioural difficulties.

More and Better Universal Services

SSLPs have extended and improved services generally, and families where there are additional needs have benefited from the expansion, particularly in terms of:

- increased playgroup, childcare and nursery provision, drop-ins and play opportunities. SSLPs funded additional sessionals for children with special needs to give them extra developmental opportunities and respite for their parents.
- increased family support, at groups or through home visits. Parents caring for disabled children or children with learning difficulties were likely to receive intensive, sustained home support.
- increased specialist health services, particularly speech and language therapy and mental health outreach, delivered in groups, to early years settings or at home.

What Parents Liked Most about SSLP Provision

- Friendly, non-judgemental, knowledgeable staff, who will find an answer if they don't know it themselves; having someone to talk to when the pressure is too much.
- Interest taken in the whole family, including them as parents, helping them to think about their own needs and their future, as well as finding services for their child.
- Having their own concerns about their child taken seriously, their experience valued and being shown how best to support their child.
- Support during the process of assessment and diagnosis and help in obtaining benefits, grants and specialist support.
- Having a few hours off each week (for example, through free or subsidised childcare sessions). Encouragement and support (for example, using childcare or having a taxi provided) to join in SSLP activities.
- Information and advice on making choices for their children; high quality early learning, play and childcare, with skilled, friendly staff who work hard to include their child.
- Seeing their child happy, coping well and making friends.

Influencing the Way Services are Delivered to Young Children with Special Needs

SSLPs have influenced other providers, like childminders and local playgroups, to be committed to equal opportunities and inclusive services, and to be flexible and responsive to families. They have demonstrated a preventive approach, for example, through speech therapists who address emerging special needs without the need for assessment or referral. They have worked to overcome the 'barriers to access' faced by

families through family support, visiting families at home, exploring with them the services they need, building their confidence to join groups, organising transport and childcare and reaching out to BME communities. SSLPs have made their own and other community facilities accessible and well-equipped, including special toys and equipment for individual children. And they have 'joined-up' services, leading to quicker, more appropriate responses for families and improved problem-solving among professionals.

Improvements in Services - Family Support

Family support services were important to children and families with special needs and disabilities. They could be structured in different ways, for example: as a small sign-posting team; a small team of experts (nursery nurses, social workers, speech and language therapist, mental health worker and so on, often working with generic family support workers); or a larger generic team often comprised of local parent workers, able to draw on 'experts' contracted to outside specialised organisations like KIDS, Home-Start or Barnardos.

Good practice was evident when family support:

- was a **core service**, working across all aspects of SSLP provision to give a coordinated package of support;
- had the **expertise** to provide specialist help to child and family;
- had the **time and capacity** to work with families over a sustained period;
- allowed for a **sensible division of roles** between specialist and generalist staff, (thus using resources most effectively).

Family Support workers assumed the role of **keyworker** for families with disabled children, coordinating services, acting as a point of contact for parents, and helping families to get information and services.

Supporting a family with severely disabled children and language barriers

One Sure Start Local Programme, in a predominantly Asian neighbourhood, works with many families with severely disabled children. Family support is the key service offered, with outreach to help parents to manage complex healthcare needs. The family support team is representative of the local community, with workers who speak several languages. One family they have worked with extensively has two children with a degenerative condition. The mother has learning difficulties. Sure Start involvement has included:

- Helping the mother to learn how to administer a nasal-gastric feed, modelling the process until she felt confident to do it herself. This was necessary as the father was often in hospital with their other child;
- Accompanying them to key appointments and running through the information afterwards to confirm understanding. Helping with follow-up calls and letters. Providing a booklet on their children's condition in their mother tongue.
- Arranging transport for out-of-town appointments and liaising with other services including physiotherapy and dieticians.
- Regularly visiting the home to provide practical and emotional support and portage home-learning.
- Advising on benefits and helping to fill in DLA forms.
- Helping to choose a nursery for their other daughter.

Home Visiting

The purpose of home visiting was to help parents support their child's development. Many programmes:

- employed portage workers, who delivered home-based learning;
- trained family support workers in parenting skills and modelling play;
- offered specialist programmes on behaviour management, continence, nutrition, sleep routines and so on;
- collaborated with social services to establish household routines.

Emotional and Moral Support

SSLPs worked in areas where families were already under pressure. Parents whose children have special needs faced additional pressures and particularly valued the help they received from family support workers during periods when they awaited news of the implications of their child's condition. There were many stories of the support offered when families were facing a crisis.

Supporting families through crisis periods

John is a single father with two children. A few years ago, his daughter Sally had a stroke which left her disabled. She used to attend the Sure Start crèche and John was involved in some of the activities for Dads. When Sally was discharged from hospital – seemingly without a care plan – he turned to Sure Start for advice. He described the help provided as a ‘lifeline’. Extra support was arranged so that his daughter could continue to use the crèche and an outreach worker made regular home visits to deliver a play programme to help her to begin re-learning skills. Sure Start also provided emotional support to John through this period and pointed him in the right direction to access the services he needed. In his words:

“Sure Start staff have been fantastic, they’ve been there for her ... I didn’t know anything to be honest, just dropped into a situation where it’s like, I’m on my own basically ... There’s so much help out there if you know the right places to look.”

Respite

Most programmes offered sessional childcare to give families a break, either regularly, or, in a minority of programmes, at times of crisis. It was provided by funding places in a nursery or playgroup, by having a flexible budget for purchasing additional childcare, by providing regular play sessions for disabled children and siblings, by matching families with specialist childminders or offering regular visits by a nursery nurse.

Giving parents a break

A Sure Start on a town-edge housing estate has a flexible childcare fund to help families under stress and children in need to access good quality childcare. This has been used to support many children with special needs and disabilities, as well as parents with learning difficulties. It is intended to supplement (but not duplicate) provision made by the County Council – for example, providing additional opportunities to promote a child’s development or to help the family through a difficult period. Most placements are made following referral by the family support manager or the inclusion worker. A contract is drawn up setting out the aims of the placement and reviewed after 6-8 weeks, then termly. Normally placements are supported for up to six months.

Moving Families On

All programmes worked to avoid dependency so that parents could cope on their own, encouraging parents to come into centres for groups, drop-in and courses, and helping them to think ahead in terms of their own aspirations and their child’s education. A parent said, *“It’s one thing you don’t get anywhere [else], help with your career. It’s like, ‘Oh, wait until your kids go to school and then you can go back’, but here it’s like, ‘No, we’ll help you do it.”*

Improvements in Services - Health Services

Specialist health services offered by SSLPs included speech and language therapy, occupational therapy, psychotherapy, psychology/mental health and more rarely - a paediatrician, complex healthcare outreach and music therapy. These staff raised understanding about development norms in their specialist area

among parents and colleagues, running training for the latter, and being a visible presence at many Sure Start activities like drop-in sessions.

Health professionals valued the scope given by the SSLP for them to identify emerging special needs at an early stage, and to offer preventive support. Several programmes had developed a screening programme to identify such needs, but not all SSLPs agreed with this process, some feeling that it meant labelling children, rather than working responsively to all their needs. However, parents were positive about needs identification and had often had concerns about the child, so were relieved when a professional broached the issue and offered help.

Identifying risk factors and targeting support to local families

One SSLP supported the development of a screening tool which provides a framework for exploring families' needs, identifying those at risk of poor outcomes and planning responses. The tool is based around a series of questions, reflecting the dimensions of the *Assessment Framework for Children in Need and their Families*². Health visitors and midwives making pre- and post-natal visits use this to explore families' needs and possible risk factors. The assessment takes about an hour to complete, in discussion with the parents, and notes are recorded electronically. These form the basis of the SSLPs' records.

Staff valued the tool for helping them to consider families' needs holistically and for providing a framework for exploring difficult issues and enabling parents to make disclosures. It has revealed high levels of isolation and depression among local mothers, enabling support to be targeted accordingly. It has not resulted in a significant increase in demand for specialist services,

but rather, sign-posting towards SSLP activities and community resources – such as baby massage where there are attachment issues, courses to build parents' confidence and 'stay and play' or BookStart sessions. The tool also provides a better basis for referral if that is needed and has helped to build up a clearer picture of the needs of the community, leading the SSLP to invest more in mental health outreach.

Health Support at Home

Health practitioners operated through home visiting, which can improve understanding of a child's needs, including the impact of the home environment and parenting capacity. It enabled practitioners to reach some of the most vulnerable families.

Reaching out to families

Lorraine's three year old son, Jason, has severely delayed language and behavioural problems. She did not send him to playgroup because she was worried about how he would behave. He slept poorly, which affected the whole family, and would go all day without speaking a word. A friend put her in touch with Sure Start. The speech and language therapist and clinical psychologist visited for several weeks, doing activities with her and Jason and suggesting things to work on until their next visit. Jason made rapid progress. In Lorraine's words:

"He's just like a totally different child ... it's unreal. Nobody believed me, he would go all day without saying nothing, he used to just point to everything and now he just says everything, like everything you say, he'll repeat it!"

Jason now attends the Sure Start nursery four mornings a week, where he has settled well, and has been referred to the local child development unit for a full assessment.

² Department of Health, 2000, Framework for the Assessment of Children in Need and their Families.

Health Support at Groups and Clinics

Much SSLP group work has a developmental focus, on speech and language (Rhyme Time and BookStart, for example), parent/child interaction and behaviour management, and physical development, motor skills and fitness. Baby massage was offered in most SSLPs. Some programmes targeted groups of these subjects at parents with particular needs. SSLP's health professionals were also offering advice to early years providers, both on children with particular needs in their settings, training early years practitioners and arranging for external specialist advice where necessary.

Improvements in Services – Early Learning, Play and Care

SSLPs have extended opportunities for all children in these areas. Of importance to children with special needs and disabilities have been:

- working with parents to promote children's early learning and development from birth onwards, through groups, drop-in, courses and home learning programmes like portage;
- expanding the availability of high quality, inclusive early years provision, both in-house and locally: upgrading buildings, training staff, buying special toys and equipment and offering specialist advice and support;
- supporting the inclusion of individual children, helping parents to choose a setting, planning ahead with staff and the family and providing hands-on support through transitions.

However, there was not a clear link between the improvements in quality in early years provision and the extent to which children with special needs and disabilities were included. While some 'flagship' nurseries attracted children with

higher support needs, many SSLPs with modest in-house facilities were working equally well with this group through inclusive crèche and play sessions, home-based learning, skilled childminders and outreach, to support children's inclusion in the setting of their parents' choice.

Early years provision was the least well embedded of SSLP services – in a few areas operating at arms length for the SSLP, with little information-sharing or collaboration between staff. Nevertheless, there were examples of good practice.

Conclusions and Recommendations for Children's Centres

- National guidance should set clear and consistent expectations about the role of Children's Centres in reaching out to disabled children and their families and in improving access to both universal and specialist services.
- Local agencies should provide Children's Centres with regular updates on the number of such children living locally. The take-up of Children's Centre services by children and families with special needs and disabilities should be monitored – which will require a consistent approach to definitions.
- Children's Centres should employ a staff member with expertise in special needs and disabilities. This responsibility could be on a shared basis across a cluster of local centres. One person on the Senior Management Team should have strategic responsibility for ensuring that the Children's Centre is meeting the needs of this group.
- Children's Centres must have sufficient capacity to undertake home-visiting if they are to reach isolated and vulnerable families, including those with disabled children. Reliance on over-

Good Practice in Providing Developmental Opportunities

About one-third of the children attending a SSLP nursery on a run-down urban estate are reckoned to have special needs. Language delay was a particular concern, reinforcing disadvantage when children started reception class. As well as establishing a 'flagship' nursery which successfully includes children with a wide range of needs, the SSLP offers extra opportunities to children aged 2-3 years, where there are developmental concerns.

Children are referred by SSLP colleagues or parents and expected to attend as regularly as possible. Two weekly sessions are offered during term-time, based on *Birth to Three Matters*, the *Foundation Curriculum* and the portage approach. Speech and language activities are a key element in every session, as well as physical play, and *Circle Time* – allowing children to explore their emotions. The group is run by an inclusion worker and a portage worker, with regular input from the speech and language therapist and clinical psychologist. Home-visiting allows for further input individually and parents are invited to join the group once a term, when they can and get feedback on their child's progress.

Each child has a play plan with identified targets, or if on the SEN Code of Practice, an Individual Education Plan. The inclusion worker keeps records on each child's progress which can be used to support their transition. Staff from feeder nurseries are invited to join the group before transition and planning meetings are organised for all children on the SEN Code of Practice, with involvement by a pre-school advisory teacher (who used to work at the SSLP).

The inclusion worker and portage worker also run a more informal drop-in for children aged 0-3 years and their parents, as part of the city-wide Early Support Programme. Again, this draws on *Birth to Three Matters* and the portage model, breaking children's learning down into small steps and providing materials and activities for parents to use to support their children's learning. A themed programme is published so parents can choose to attend those sessions they feel are most relevant.

stretched children's services is not, at present, a realistic alternative, although in Sure Start Local Programmes there were positive examples of collaboration with social services, particularly around supporting parents with learning difficulties.

- Speech and language therapy and mental health services should be available in all Children's Centres operating in disadvantaged communities, with sufficient capacity to work with individual children and their parents and to promote skills and awareness in early years settings and through parents' groups.
- Children's Centres should form a key element in local strategies – including the Children and Young People's Plan - to achieve a shift in service delivery, towards early intervention. Assessing the extent to which key services (health, family support and SEN provision) are offered on a preventive basis should be a central element in the new performance management framework for Children's Centres, local authorities and partner agencies.
- Improving the availability of affordable childcare for disabled children should be a priority in local childcare strategies (including for parents who care full-time for their children). Children's Centres should consider the scope for funding additional childcare sessions for this group, particularly through crisis periods.

- As integrated programmes of support, Children's Centres should play an outreach role to support the inclusion of children with special needs and disabilities and to raise skills and awareness in local early years settings. Having an area SENCO (Special Educational Needs Coordinator), pre-school advisory teacher or a special needs outreach worker based in the SSLP/Children's Centre provides a valuable basis for building relationships.
- Supporting transitions to school and beyond SSLP/Children's Centre services will remain an area that requires attention in the future.

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Further information

Further copies of this summary are available from:

DfES Publications, PO Box 5050, Sherwood Park, Annesley, Nottingham, NG15 0DJ;

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Quote reference NESS/2006/SF/019

Copies of the Full report on Services for children and families with special needs and disabilities are available from the above address or from the Sure Start website www.surestart.gov.uk

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Further information about the National Evaluation of Sure Start (NESS) can be found at www.bbk.ac.uk

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