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## National evaluation report

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

**SureStart**

Report 019



Evidence  
& research

Research Report  
NESS/2006/FR/019

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

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education and Skills.

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***The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education and Skills***

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The views expressed in this report and the conclusions drawn are those of the author alone.

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## **Executive Summary**

### **Background**

Sure Start Local Programmes (SSLPs) were established in successive 'waves' from 1999, to provide integrated support to young children and families living in many of England's most disadvantaged communities. 'Special needs' was one of five core services which SSLPs were required to deliver, alongside outreach and home-visiting, family support, early learning, play and childcare, and healthcare.

The National Evaluation of Sure Start (NESS) was set up to assess the impact, implementation, community characteristics and cost effectiveness of SSLPs. This report is one in a series of 'snapshot' studies within the implementation module, intended to explore how SSLPs developed key aspects of their services and to learn lessons from their practice. The aims of the research were to explore:

- how SSLPs were meeting the needs of children and families with special needs and disabilities - both in terms of universal and specialist provision;
- how SSLPs had improved services for this group and which factors were significant in enabling or impeding progress;
- how practice varied between SSLPs and for different groups.

### **Methodology**

The research design was based on a focused literature review, interviews with national stakeholders, a review of NESS evidence, web searches and pilot fieldwork in three SSLPs. This informed the research hypotheses – which provided a framework for assessing local practice - and the selection of twelve fieldwork sites. Because the project aimed to learn from effective practice, the sample of fieldwork SSLPs was skewed towards those that appeared to be working effectively or innovatively with children and families with special needs and disabilities (based primarily on NESS evidence). They formed a representative sample of all SSLPs, in terms of socio-economic and ethnic profile.

Each fieldwork visit involved a review of literature and information for parents; interviews were undertaken with the programme manager, head of each service area, special needs lead and a variety of other staff; discussions with parents were carried out; short questionnaires on key services and special needs numbers were completed; and phone interviews with partner organisations and key board members were undertaken. Almost 150 practitioners were interviewed, over 40 partner agencies or board members and more than 30 parents.

## Definitions - who are we talking about?

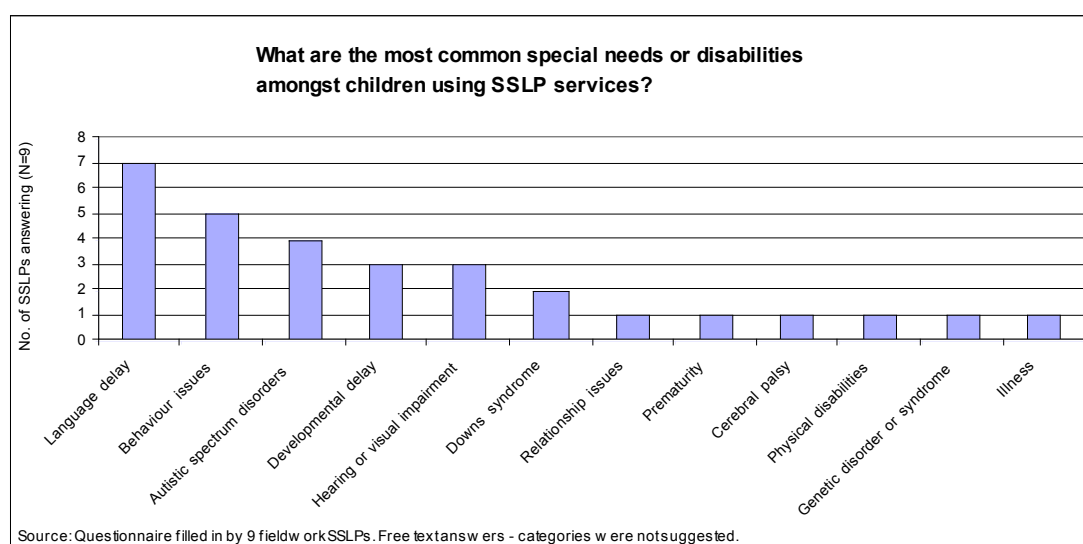
Children and families with special needs and disabilities were the focus of this research, using the definition established by the 2002 Sure Start guidance:

*“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.”<sup>1</sup>*

The programmes visited estimated that they were working with between 5 and 120 children with special needs and disabilities, with an average of just over 40 – or about 5 per cent of the age cohort.<sup>2</sup> The chart below shows their perceptions of the most commonly occurring special needs amongst these children.



## Key findings

Overall, the research findings were positive, but practice varied widely – in terms of which services were offered and how far they were targeted at children and families with special needs and disabilities. This influenced SSLPs’ success in reaching families with disabled children and those with more significant and complex needs. One quarter of the SSLPs visited said had worked with few, if any, such children. Given that the fieldwork sample was skewed towards those working more extensively with this group, this suggests that there are no grounds for complacency.

<sup>1</sup> DfES, 2002, *Supporting families who have children with special needs and disabilities*.

<sup>2</sup> Caution should be attached to these figures, as SSLPs used different approaches for counting special needs numbers. This is discussed further in the full report.

Every programme was working responsively with the wider group of children with special needs – i.e. moderate delay or difficulties of some sort, most commonly language delay and behavioural difficulties – and their families.

### **Targeted or universal services?**

Services targeted at children and families with special needs and disabilities represent a small element of SSLP provision. Of greater significance to this group is the way SSLPs have extended and improved universal services - early years, health and family support – with increased capacity in key services, improvements to the built environment, flexible staffing and funding arrangements all providing a better basis for inclusion and participation.

However, some degree of targeting – for example, employing a special needs expert and offering services such as portage, extra childcare sessions and special playgroups – was associated with improved ‘reach’ of children with more significant and complex needs. Where SSLPs were proactive in reaching out to such families, they were in contact with many more - in contrast to those that assumed that there were none living locally or that they were well served by local specialist and voluntary services.

### **Recommendations**

- 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 more consistent approach to definitions.
- Children’s Centres should employ a staff member with expertise in special needs and disabilities - this 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.

### **Which services were most significant?**

#### **Family support**

Family support emerges as the most significant SSLP service for children and families with special needs and disabilities - helping families to cope through crisis periods, to access relevant services and benefits, building parents’ skills and confidence in supporting their child’s development and giving them some respite from their caring responsibilities. More broadly, family support workers



play a critical role within SSLPs, by reaching out to vulnerable groups, joining-up services around children and families and linking with health and early years workers.

Home-visiting was particularly important for reaching families whose children have more significant and complex needs, parents with learning difficulties and those who face language and cultural barriers to services. However, the balance between empowering parents and engendering dependency needs to be carefully managed – there is a need to maintain a clear focus on '*moving families on*': enabling parents to cope themselves, to access relevant services and community facilities and to plan for the future.

Family support teams were being cut in some areas, as other services were prioritised in the move towards Children's Centres.

### **Recommendations**

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

### **Specialist health services**

The increased availability of specialist health services – in particular, speech and language therapy and mental health outreach - is another key area of improvement for children with special needs and disabilities. Early childhood is a critical developmental period, yet such services are seldom available to children under five years of age. Health specialists seconded to SSLPs were working with much younger children, on a preventive basis:

- making home visits to develop parents' skills in promoting their child's development and managing their behaviour – often with rapid improvements;
- awareness-raising and 'mainstreaming' effective practice by running groups and courses for parents and by training early years and other SSLP staff.

However, where staff carried large caseloads, this limited the scope for developing their wider preventive role – reducing the influence on local mainstream practice. In some areas, specialist health posts were being reduced due to pressures on NHS budgets.

## **Recommendations**

- 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.

## **Early learning, play and childcare**

SSLPs have worked to extend and improve early learning, play and childcare opportunities for local children. High expectations of inclusive practice, together with flexible staffing and funding arrangements, have helped to make these accessible to those with special needs. SSLPs have also offered groups and other activities to increase parents' skills and confidence in promoting their children's early learning and development. In addition, for children with special needs and disabilities, most SSLPs:

- funded extra sessions to provide additional learning opportunities and to give parents some respite – described as a 'lifeline' by some;
- had flexible funding arrangements to support the inclusion of individual children – making minor adaptations, buying special toys and equipment or providing extra support for a limited period;
- offered home-learning programmes such as portage, through their family support service. Family support workers also helped parents to make informed choices of early years setting, liaising with staff to support a smooth transition.

However, early years provision was the least well embedded of SSLP services – in a few areas, operating at arms length from other services. A key challenge for Children's Centres will be to 'add value' to local early years provision, forging links between services to facilitate forward planning and supported transitions for children with special needs and disabilities; to develop staff skills and confidence; and to enable holistic responses to children's needs.

## **Recommendations**

- 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, 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 remained an area for development in most SSLPs.

## **What works? Lessons for SSLP and Children's Centre managers**

The final chapter of the report provides a checklist of 20 characteristics of effective practice, for consideration by local managers. Key factors include:

- **Leadership:** a clear commitment to including children and families with special needs and disabilities on the part of the Programme Manager and senior management team. Reflected in literature and policies and embedded in all aspects of practice – from staff induction through to service review.
- **Listening to parents:** finding out what parents of children with special needs and disabilities want, identifying gaps in provision and barriers faced in accessing services. Reviewing this regularly. Ensuring parents have a voice in governance structures.
- **Needs-based planning and review:** finding out the needs profile of the local population, using information from partner agencies to plan and review services.
- **Establishing strong working relationships with local statutory and voluntary agencies,** a clear understanding of the Children's Centre's role and how it can 'add value' to local services. Agreeing protocols for information-sharing and referrals.
- **Employing a special needs/disability expert to undertake some direct work with children and families,** advise and support colleagues and influence SSLP strategy and practice. This role could be shared with other Children's Centres or combined with an area senco/pre-school advisory teacher post.

- Ensuring staff have the skills and awareness they need to work effectively with children and families with special needs and disabilities – including training in disability awareness and safeguarding disabled children. Health, social care and SEN specialists need to have time protected for preventive work – raising awareness, contributing to groups and activities, advising and training colleagues.
- Exploiting the potential of joined-up working – in terms of reaching vulnerable groups, holistic responses to individual needs, forward planning and supported transitions. ‘Enablers’ include: co-locating staff in multi-disciplinary teams, joint training and shared information systems.
- Establishing information systems which allow for appropriate sharing between colleagues, including a reliable chronology of service use by children and families and a system for logging concerns about risks. Forums for discussing and reviewing cases can help to ensure that practice is safe and effective.
- Collecting information on service use and outcomes – able to be analysed for different groups, including those with special needs and disabilities and minority ethnic groups. Establishing clear monitoring and reporting requirements for commissioned services.

## Part One: Introduction

1. Background to the research
2. Aims of the research
3. Methodology
4. Definitions - who are we talking about?
5. Research and policy context

### 1.1 Background to the research

*“Sure Start aims to transform the life chances of young children, particularly those with special needs and disabilities, who live in areas of disadvantage ... 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.”* (DfES guidance to Sure Start Local Programmes, 2002)

**Sure Start Local Programmes** (SSLPs) were created with the aim of getting young children in over 500 of England’s most deprived neighbourhoods off to a better start in life. Established in successive ‘waves’ from 1999, SSLPs were intended to expand and improve services for children aged 0-4 years and their parents and carers<sup>3</sup>, working with voluntary and statutory agencies to deliver integrated programmes of support. SSLPs were allowed discretion over which services to develop, in the light of community needs, but all were expected to provide five core services:

- outreach and home visiting
- support for families and parents
- support for good quality play, learning and childcare
- primary and community health care and advice
- support for children and parents with special needs.<sup>4</sup>

Guidance was published in 2002 – building on the experience of the early SSLPs - to raise awareness of the particular needs of children and families with special needs and disabilities and to help programmes become more accessible and responsive.<sup>5</sup>

**The National Evaluation of Sure Start** (NESS) is a major research programme, incorporating five areas of study:

- assessing the impact of SSLPs on local children and families;
- exploring their implementation and how they put policy into practice;
- gathering evidence on the local context in which SSLPs operate;
- analysing their cost-effectiveness;
- supporting SSLPs to evaluate their own services.

<sup>3</sup> For ease of reference, where the text refers to parents this should be assumed to include carers.

<sup>4</sup> DfES, 1999, *Guidance to SSLPs*

<sup>5</sup> DfES, 2002, *Supporting families who have children with special needs and disabilities*

Themed studies such as this one form part of the ‘implementation module’. They are descriptive, not evaluative, studies: intended to describe key aspects of SSLP services and draw lessons from their implementation, not to judge how well SSLPs are working overall or their impact.

## **1.2 Aims of the research**

This project aimed to explore:

- how Sure Start Local Programmes developed services to meet the needs of children and families with special needs and disabilities - both in terms of core (i.e. mainstream) and specialist (i.e. 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 factors which acted as barriers to progress.

## **1.3 Research methodology**

The research design was based on a focused literature review, interviews with national stakeholders, a review of evidence already gathered within the National Evaluation of Sure Start, web searches and pilot fieldwork in three SSLPs. This informed the research hypotheses, which provided a framework for assessing local practice. While this was not an evaluative piece of work, any judgements on the effectiveness of SSLPs made in the course of this report are based on how their practice measured up against the hypotheses, as well as feedback from parents, local practitioners and partner agencies.

Because the project aimed to learn from effective practice, the sample of fieldwork SSLPs was skewed towards those that appeared to be working more extensively or innovatively with children and families with special needs and disabilities. A shortlist of 50 SSLPs was compiled, drawing primarily on NESS evidence including:

- the extent of special provision offered (national survey)
- year-on-year spending on SEN (cost effectiveness module)
- ratings of SSLP practice in terms of multi-agency teamwork, access to specialist services, strategies for identifying users and other key characteristics assessed in the programme variability study.

Twelve SSLPs were selected to produce a sample that was representative in terms of socio-economic and BME profile, based on NESS contextual data<sup>6</sup> and including a spread in terms of lead partner, region and type of area.

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<sup>6</sup> The Local Context Analysis (another strand of NESS) identified 5 ‘types’ of SSLP community, based on socio-demographic and economic characteristics, typified by relative deprivation and the proportion of ethnic minority families. The sample of fieldwork sites was representative of these 5 types.

Fieldwork visits were carried out between February and July 2006. Each visit involved:

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

Almost 150 practitioners were interviewed, over 40 partner agencies or board members and over 30 parents. Detailed notes were taken and recorded against the project hypotheses. Annex A provides further detail on the methodology and the hypotheses.

#### **1.4 Definitions - who are we talking about?**

Children and families with special needs and disabilities are the focus of this report, using the definition established by the 2002 Sure Start guidance:

*“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.”<sup>7</sup>*

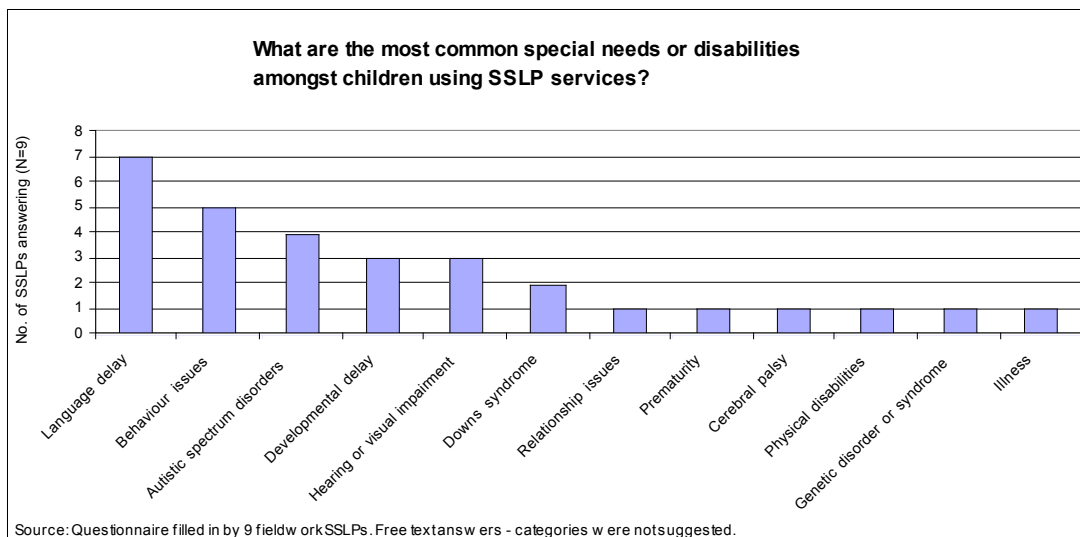
The programmes visited differed in their interpretation of special needs and disabilities and in how they counted such children. Broadly speaking:

- **‘Special needs’** was the term most widely used to describe children with moderate developmental delay or behavioural difficulties. The chart below shows SSLP perceptions of the most common special needs. The programmes visited estimated that they were working with between 5 and 120 children with special needs, with an average of just over 40 – or about 5 per cent of the age cohort.<sup>8</sup>

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<sup>7</sup> DfES, 2002 (as before).

<sup>8</sup> The research raises serious doubts about the validity of these figures, shared by local managers. This is discussed further at 3.2: Registrations, referrals and reporting.



- Some SSLPs preferred to use the term **'additional needs'**, to include groups such as Children in Need and others where there were broader concerns about the impact the home environment and parenting capacity may have on a child's development and well-being;<sup>9</sup>
- **'Disability'** is a more clearly defined term, used to describe more profound and enduring needs.<sup>10</sup> Three-quarters of the programmes visited were working with a small number of disabled children, while the remainder said they had little contact with this group.

To put these figures in context, nationally 11 per cent of children in maintained nursery schools have special educational needs (SEN), including one per cent with statements, providing for extra support from the local authority or other agencies.<sup>11</sup> An estimated six per cent of under-fives are disabled (most of whom have SEN), although the figure used for local planning purposes remains about three percent.<sup>12</sup> Over the last two decades the number of disabled children has increased by more than half and research points to some important trends including:

- rising numbers of children with mental health problems, diagnoses of autistic spectrum or attention deficit hyperactivity disorders;

<sup>9</sup> Children are considered to be "in need" under the Children Act 1989 if they are unlikely to achieve "a reasonable standard of health or development", if their health or development is likely to be impaired without the provision of social services, or if they are disabled.

<sup>10</sup> The Disability Discrimination Act 1995 defines a disabled person as someone with "a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities."

<sup>11</sup> The Education Act 1996 defines SEN as "a learning difficulty, which calls for special educational provision" – i.e. requiring additional or different provision to overcome barriers to learning. Most but not all disabled children have SEN. Figures from DfES, 2006, *SEN in England, January 2006*; equivalent figures not collected for other types of provision.

<sup>12</sup> Campbell et al, March 2005, *The National Centre for Early Intervention Feasibility Study*.



- a steep rise in severe disability and complex needs, linked to increased survival of premature babies and children with degenerative conditions.<sup>13</sup>

## 1.5 Research and policy context

### Research overview

There is a large body of evidence about the additional pressures and barriers to services experienced by families with disabled children.

- The annual costs of bringing up a disabled child are three times those for a non-disabled child. About 55% of families with disabled children live on a low income.<sup>14</sup> Mothers with disabled children are seven times less likely to be able to get work, mainly due to a lack of suitable childcare.<sup>15</sup>
- Parents with disabled children face higher levels of stress. Key contributory factors include sleep and behaviour problems, as well as difficulties related to employment, finances and accessing benefits and services.<sup>16</sup> Demand for family support far outstrips supply “*with tight eligibility criteria and long waits for assessment and service provision.*”<sup>17</sup> Parents of disabled children particularly want help with:
  - information, peer support and counselling;
  - support with caring, with access to occasional short breaks;
  - sleep and behaviour programmes;
  - home-based learning – such as portage or early bird, for autistic children;
  - key workers – to help with information, communication and care coordination.<sup>18</sup>
- Finding out about services and dealing with providers can be one of the most difficult aspects of caring for a disabled child. Families with disabled children have contact with an average of 10 different professionals and over 20 visits per year to hospitals and clinics – and report a ‘constant battle’ to find out which services are available and the role of different agencies.<sup>19</sup> Access to disability equipment to help with day-to-day living is a key area of concern.<sup>20</sup>

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<sup>13</sup> Campbell et al, 2005; NSF standard 8 research paper (as below); PMSU, 2005 (as below).

<sup>14</sup> Research summary informing DH, 2004, *National Service Framework for Children, Young People and Maternity Services – Standard 8*.

<sup>15</sup> Prime Minister’s Strategy Unit, 2005, *Improving the Life Chances of Disabled People* (drawing on Family Fund and General Household Survey data, 2002).

<sup>16</sup> DH, 2004, NSF Standard 8 research summary

<sup>17</sup> Audit Commission, 2003, *Let me be me: A handbook for managers and staff working with disabled children and their families*.

<sup>18</sup> PMSU, 2005 (consultation with parents).

<sup>19</sup> DH, 2004, NSF Standard 8 research summary

<sup>20</sup> Audit Commission, 2003.

- Black and minority ethnic (BME) families with disabled children have a lower take-up of services and benefits, feel less well informed and less able to access services.<sup>21</sup> Language and cultural barriers and a lack of staff confidence can mean that they face the “double discrimination” of being disabled and being from a minority ethnic group. This tends to be worse in predominantly white areas, with lower awareness and weaker community support networks.<sup>22</sup>

There are also well documented concerns about how far disabled children – and the much wider group with special educational needs (SEN) – are able to access early learning and childcare opportunities.

- An Ofsted review of early years provision in the private and voluntary sectors found that “*inconsistency and lack of joined-up support created unnecessary barriers*”. Children with complex health needs and challenging behaviour were the hardest to include – requiring specialist training and multi-agency support – but creative thinking, ‘can-do’ attitudes and low cost adaptations can make a great difference.<sup>23</sup>
- Earlier research by the Audit Commission found that arrangements for supporting pre-school children fell far short of the level of advice and support offered to older children with SEN, and that local authorities’ responsibilities towards children with statements limited the scope for preventative work. Some groups faced more barriers to services: “*Whether and how children’s needs are identified appears to be influenced by a range of factors, including their gender, ethnicity and family circumstances, where they live and which school they attend.*”<sup>24</sup>
- Another Audit Commission report highlighted the difficulty families with disabled children have in finding suitable and affordable childcare - associated with concerns about staff skills and capacity, as well as health and safety considerations.<sup>25</sup>

## Policy overview

This study has been carried out in the context of major reform to children’s services, described below under three themes:

- Structural reform of children’s services
- Improving services for children and families with special needs and disabilities
- Extending high quality early years and childcare provision

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<sup>21</sup> PMSU, 2005.

<sup>22</sup> Simon, J., 2006, *Diversity Matters*, Council for Disabled Children.

<sup>23</sup> Ofsted, Sept 2005, *Removing barriers: a ‘can-do’ attitude*

<sup>24</sup> Audit Commission, 2002, *Special educational needs: A mainstream issue*

<sup>25</sup> Audit Commission, 2003, *Services for disabled children*

## Structural reform of children's services

The *Every Child Matters* Green Paper,<sup>26</sup> enshrined in the *Children Act 2004*, paved the way for integrated children's services, with a clearer emphasis on early intervention. Children's Trusts are expected to be in place across the country by 2008, with integrated local delivery through a network of children's centres and extended schools. The Act places a duty on public bodies to work together to safeguard and promote the well-being of children and young people, establishing five key outcomes:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being.

Other key initiatives arising from *Every Child Matters* include:

- the development of a Common Assessment Framework – a single, holistic framework for assessing and responding to children's additional needs;
- the introduction of Lead Professionals to coordinate services for children and young people known to more than one agency;
- systems for sharing information across service boundaries.

In parallel, the *National Service Framework for Children, Young People and Maternity Services* (the 'NSF') set out 10-year agenda for improving health and social care services for children, establishing a set of national standards. Standard eight expects that:

*"Children and young people who are disabled or who have complex health needs receive coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives."*<sup>27</sup>

Key themes within this wide-ranging agenda include:

- enabling disabled children to participate fully in family and community life;
- organising services around the needs of children and families, with coordinated multi-agency assessments and service provision;
- identifying needs and intervening early to support children's development;
- involving children and families in decision-making about the provision made for them and in shaping public services.

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<sup>26</sup> HM Government, Sept 2003, *Every Child Matters*

<sup>27</sup> DH, 2004, *National Service Framework for Children, Young People and Maternity Services – Standard 8: Disabled Children and Young People and those with Complex Health Needs*.

## Improving services for children and families with special needs and disabilities

In parallel, there has been a stream of initiatives aimed at improving outcomes for children with special needs and disabilities and their families.

*Together from the Start* (2003)<sup>28</sup> provided guidance for professionals working with very young disabled children and their families, to improve practice around early identification, intervention and multi-agency support for families. Key themes include:

- sensitive communication with parents around news-breaking, coordinated assessments and care planning;
- joining-up service provision – with key workers for children with complex needs and their families and improved information-sharing between agencies;
- family-centred approaches, with positive attitudes towards disability, partnership working with parents and family support networks;
- joining-up service planning, commissioning and review.

The *Early Support Programme*<sup>29</sup> took forward the principles set out in *Together from the Start*, piloting effective approaches and developing a practical resources and tools, including:

- a Family Pack and Family File to help with service coordination;
- Professional Guidance promoting the Early Support approach;
- a Service Audit Tool to evaluate services and plan for improvement;
- information booklets for parents on particular conditions and disabilities.<sup>30</sup>

*Removing Barriers to Achievement: The Government's Strategy for SEN* (2004)<sup>31</sup> set out the Government's vision for improving opportunities for children with SEN and disabilities, in the context of the wider reform agenda. Early intervention is 'the cornerstone' of the strategy – emphasising the critical importance of the early years in children's development. Amongst other things, it pledges:

- to make the principles set out in *Together from the Start* and embedded in *the Early Support Pilot Programme* integral to practice nationally;
- a new strategy for childcare for children with SEN and disabilities, promoting a more integrated approach and better information for parents.

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<sup>28</sup> DfES/DH, 2003, *Together From the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*

<sup>29</sup> Launched Sept.2002 as the Early Support Pilot Programme. See [www.earlysupport.org.uk](http://www.earlysupport.org.uk).

<sup>30</sup> Children's Centres are expected to use these resources in planning and providing services for families with disabled children (DfES, Nov 2005, *Sure Start Children's Centres: Practice Guidance*).

<sup>31</sup> DfES, 2004, *Removing Barriers to Achievement: The Government's Strategy for SEN*.

*The Disability Discrimination Act 1995*, as extended by the *SEN and Disability Act 2001*, requires early years providers not to treat disabled children less favourably than others and to make 'reasonable adjustments' to ensure that they have access to the curriculum, the built environment and information. From December 2006, all public bodies are under a general duty to promote equality of opportunity for disabled children and adults, eliminate discrimination and harassment and to promote positive attitudes and participation. They will be expected to involve disabled people in planning and delivering services, including in the preparation of Disability Equality schemes.

*Improving the Life Chances of Disabled Children*<sup>32</sup> – a report from the Prime Minister's Strategy Unit in 2005, put forward a 20-year strategy to improve opportunities for disabled people. Its recommendations were accepted in full by the Government. Improving support for families with young disabled children was one of the four key areas for improvement highlighted. Priorities include:

- timely access to equipment;
- high quality, flexible and affordable childcare;
- key workers for all families with high support needs to coordinate services and provide information.

Finally, in the Spring 2006 Budget, the Chancellor of the Exchequer announced a Treasury-DfES review of services for disabled children, to inform the 2007 Comprehensive Spending Review. Key themes emerging from work to date include the need to encourage more of a focus on early intervention, greater coordination between services and improving workforce skills.<sup>33</sup>

#### Extending high quality early years and childcare provision

The last decade has seen great expansion in the availability of early years education and care. A ten-year national strategy - *Choice for parents, the best start for children*<sup>34</sup> - is underway to improve the availability, quality and affordability of early years provision. This recognises the difficulty that families with children with special needs and disabilities can have in finding appropriate, affordable childcare and expects local authorities to take account of their needs in planning and delivering services.

Key elements of the strategy are enshrined in the *Childcare Act 2006*. This places a duty on local authorities to ensure sufficient childcare for working parents and those trying to find work – in particular, for families on lower incomes and those with disabled children – requiring them to take a lead on planning, supporting and delivering childcare and on improving information to parents. The Act also requires local authorities, NHS and other agencies to work together to improve outcomes for all young children and to reduce inequalities between them.

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<sup>32</sup> PMSU, 2005, *Improving the Life Chances of Disabled People*.

<sup>33</sup> HMT, DfES, 2007, *Policy review of Children and Young People: a discussion paper*.

<sup>34</sup> DfES, Dec 2004, *Choice for parents, the best start for children*.

At local level, integrated services are to be provided through *Sure Start Children's Centres*, which will build on the experience of SSLPs. The Government is committed to delivering 3,500 Children's Centres by 2010 - with one in every community - and the expectation is that most SSLPs will become Children's Centres. Local authorities will be responsible for delivering this offer, working with primary care trusts, private and voluntary sector providers. Children's Centres are intended to be 'one-stop shops' for young children and their families. Services will vary according to the needs of the community, with those in the most disadvantaged areas (where SSLPs are) providing:

- integrated childcare and early learning
- a childminders network
- parenting education and family support services
- education, training and employment services
- health services
- information and facilitating access to wider services.<sup>35</sup>

The *Sure Start Children's Centres Practice Guidance* devotes a chapter to working with disabled children – with the clear expectation that “*Disabled children should be fully included in all services provided by children's centres.*” It highlights the importance of:

- family support services – including help with sleep and behavioural problems, caring for children with complex needs, practical support and day-to-day care;
- portage and other home learning and play programmes;
- key workers for those with severely disabled children;
- speech and language therapy, physiotherapy and occupational therapy to promote children's development;
- ensuring that children with special needs and disabilities access their entitlement to early years provision;
- information, particularly for families in minority ethnic communities;
- professional support and counselling for parents, especially after a diagnosis;
- where possible, the provision of multi-agency services from the centre.

The guidance makes it clear that local authorities should consult parents and carers of disabled children and involve voluntary sector partners in developing their services. Take-up should be monitored and action taken to overcome barriers to access. The Government are also consulting on a framework for performance management of early childhood services and children's centres, reflecting the *Every Child Matter* outcomes. This will include an indicator on 'accessing excluded groups'.<sup>36</sup>

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<sup>35</sup> DfES, Nov 2005, *Sure Start Children's Centres: Practice Guidance*

<sup>36</sup> DfES, 27 July 2006, letter to local authority Directors of Children's Services from the Sure Start Director.

## **Part Two: How have SSLPs improved services for children and families with special needs and disabilities ?**

### **2.1. Approaches to special needs**

#### **Key messages**

The twelve programmes visited in the course of this research varied significantly in their approach to special needs – in terms of:

- the profile given to special needs in SSLP policies, literature and imagery;
- if they employed a staff member with expertise in special needs or disabilities;
- the extent of special or targeted services offered.

This had some influence on their success in reaching families with children with disabilities or more significant and complex needs - particularly if the SSLP was known locally for working with this group. One quarter of the SSLPs visited said they had worked with few, if any, children with more significant and complex needs and did not perceive a clear role in doing so, given the presence of specialist statutory and voluntary organisations. Given that the choice of fieldwork SSLPs was skewed towards those working more extensively with children and families with special needs and disabilities, this suggests that there are no grounds for complacency.

However, every programme was working responsively with the wider group of children with special needs – i.e. moderate delay or difficulties of some sort, most commonly language delay or behavioural difficulties – and their families.

Services targeted at children and families with special needs and disabilities represent a small element of SSLP provision. Of greater significance to this group is the way SSLPs have extended and improved universal services - early years, health and family support services – with increased capacity in key services, improvements to the built environment, flexible staffing and funding arrangements. All providing a better basis for inclusion and participation.

More broadly, SSLPs have exerted a positive influence on the way services are delivered to this group – in line with the reform agenda for children's services:

- setting high expectations of inclusive practice
- offering services on a preventive basis
- reaching out to vulnerable groups
- joining-up services around children and families.

## Chapter contents

1. Profile of 'special needs' in fieldwork SSLPs
2. Special needs experts
3. Special and targeted provision
4. Extending and enhancing universal services
5. Influencing service delivery

### 1. Profile of 'special needs' in fieldwork SSLPs

The SSLPs visited differed significantly in the profile given to special needs in their policies, literature and publicity materials and in day-to-day language and culture. The key influence on this was the Programme Manager and/or senior staff members – many of whom had personal or professional experience of special needs and disabilities.

While every SSLP had strong equal opportunities policies, some made no reference to children and families with special needs and disabilities and were short on specifics about what their policies meant in practice – for example, in terms of planning, staffing arrangements, additional resources, development opportunities or working with parents. Several SSLPs featured case studies and images of children and families with special needs and disabilities in their annual reports and other literature, while others made no reference to this group. It is difficult to assess the impact of policies, literature and imagery – but it was highlighted an area for improvement by parents of children with special needs, in the only two SSLPs which had commissioned local evaluations of their views [see box].

<b>Recommendations made by parents of children with special needs and disabilities</b>	
<p><u>SSLP 1</u></p> <ul style="list-style-type: none"> <li>• Ensure the profile of disability is raised at all forums, meetings, events and activities and that there is representation from parents.</li> <li>• Some services and planning of events need to take into account more the needs of disabled children/parents and develop a more welcoming policy.</li> <li>• Look at the accessibility of premises and events both in terms of physical access and attitudes ... Be flexible and look at individual needs of families.</li> </ul>	<p><u>SSLP 2</u></p> <ul style="list-style-type: none"> <li>• All services must be welcoming to both the family and child.</li> <li>• Need to improve the diversity and positive nature of the imagery within the centre.</li> <li>• An inclusive attitude is key for all those working within the centre, irrespective of the post ... All members of staff take inclusion responsibility within their own role.</li> </ul>
<p><i>Source: Local evaluations carried out in 2 fieldwork SSLPs.</i></p>	

The approach to special needs evident in SSLP policies and literature tended to be reflected in language and attitudes on the ground, observed during fieldwork. Where special needs had more profile, staff tended to be more confident in describing their work with this group and to be working with some children with significant and complex needs. By contrast, where special needs



had a lower profile, staff were more hesitant in describing their work with these children – and what they might do that was additional or different - and were less likely to have worked with disabled children with more complex needs or to perceive a role in doing so. Parents in a minority of areas regretted that staff assumed that others – specialist statutory services or voluntary organisations - were already helping them or that they perhaps would not want to use the same services as other families.

“Of course you go to the [early years assessment] Centre and everyone else sort of signs you off, because you’re getting everything there.”

Mother of a disabled child

## **2. Special needs experts**

Half of the SSLPs visited employed a special needs/disability worker, usually based on their outreach team. They played a variety of roles, including:

- leading on supporting children and families with more significant and complex needs – making home visits to work with the child and their parents on activities to promote their development and helping to establish routines;
- helping families to access relevant services, community activities and benefits - sometimes taking on an advocacy role;
- working with parents to plan and support transitions to early years settings;
- advising colleagues, special needs, reviewing cases with them and providing some training to early years and family support staff;
- in several areas, running targeted groups for children with special needs.

Special needs outreach workers had a range of professional backgrounds – voluntary sector, local authority SEN service, portage and nursing – bringing with them valuable skills, knowledge of local services and professional contacts. This made for easy referrals – making it more likely that specialist colleagues would direct families to the SSLP and facilitating external referrals. A few combined their SSLP role with being area SENCO or a pre-school advisory teacher – providing an entrée for influencing practice in early years settings and supporting transitions.

In several programmes, the special needs expert was a key staff member - on the senior management team and 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.

### 3. Special groups, activities and services

Just over half the SSLPs visited offered targeted groups and activities for children with special needs and disabilities. Many had a developmental focus – for example, language development or behaviour management – while others simply provided opportunities for parents and children to ‘stay and play’ in a supported environment, with more staff present and special toys and activities. However, some SSLPs were uncomfortable with the concept of targeted or special provision, expressing concerns about the possible stigma associated with separate provision or simply a desire to ensure that all SSLP activities were fully inclusive.

This was one area where staff and parent attitudes diverged. Feedback from parents of children with special needs – in fieldwork interviews and in two SSLP local evaluations – suggested that some parents, particularly those whose children have more significant or visible needs, want targeted provision. Parents interviewed were very positive about the special play sessions and targeted groups that they had attended and in particular, the opportunity this gave them to share experiences with others in similar circumstances. For some, this had given them the confidence to go on and join other SSLP activities.

#### What parents said ...

“It’s just good to know that ... there are people in a similar situation to yourself, that you’re not on your own.”

“When your kid’s been in hospital, if you talk to somebody who hasn’t been there ... you can seek their advice, but they haven’t got a clue ... They don’t know what it’s like to see their child going down under the anaesthetic. But it would be good support to sit and talk to somebody who has been through it - they would know the feelings, wouldn’t they?”

“Lauren’s starting to notice for herself that she’s different from the other kids, so I think it’s 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.”

Many SSLPs had offered special parents groups at some point, but most had ceased due to declining numbers.<sup>37</sup> Parents appeared to value activities which allowed them and their children to spend time together out of the home,

<sup>37</sup> The exception here was a SSLP-supported group for parents whose children had a particular condition, open to a much wider catchment area (city-wide).

whilst providing some learning and social opportunities, more than they valued parents groups.

The only targeted service, offered in nearly half the SSLPs visited, was portage.<sup>38</sup> Most portage workers were based on the family support/outreach team, although one SSLP commissioned the County Council to provide an enhanced service to local children. Where portage was offered, it was valued highly by parents. However feedback from senior managers was mixed – with some concerns expressed that it was a relative costly service, possibly lacking in rigour, as well as concerns about dependency, as portage workers were drawn into wider family support roles. Consequently, portage had been cut in several SSLPs, reverting to the more limited service funded by the local authority.

#### **4. Extending and enhancing ‘universal’ services**

Services targeted at children and families with special needs and disabilities (as described in this chapter so far) represent only a small element of SSLP provision.<sup>39</sup> Of greater significance to this group is the way SSLPs have extended and improved universal services – in particular, early years provision, health and family support. Increased capacity in key services, improvements to the built environment, flexible staffing and funding arrangements provide a better basis for inclusion and participation by children with special needs and disabilities and their families.

Family support, health and early years services are described in detail in the following chapters, but key developments include:

- an expansion in playgroup, childcare and nursery provision, and a wide variety of groups and drop-ins offering fun activities for parents and children. Most SSLPs were funding additional (free) childcare or nursery sessions for children with special needs to provide extra developmental opportunities and to give their parents some ‘respite’ from their caring responsibilities;
- increased availability of family support, through group activities or home visits where needed. Parents caring for disabled children and those with learning difficulties were likely to receive home visits on a more intensive and sustained basis;
- increased availability of specialist health services - in particular speech and language therapy and mental health outreach – delivered through groups with a developmental focus, or for individual children, home visits and outreach to early years settings.

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<sup>38</sup> Portage is a home-learning programme for young children with special needs and disabilities. Portage workers offer play and learning activities tailored to the child’s needs, working with parents in the home.

<sup>39</sup> Unreliable data make it impossible to quantify what percentage of SSLP provision is ‘special needs’ provision.

### Which aspects of SSLP provision did parents value most?

Parents of children with special needs or disabilities were interviewed in every SSLP visited. They particularly valued:

- Friendly, non-judgemental, knowledgeable staff – who will find the answer, even if they don't know it themselves. Having someone to talk to unconditionally when the pressure gets too much.
- The interest shown in the whole family's needs - supporting them as parents, helping them to address their own issues and to start thinking about the future – as well as finding out about local services for their child.
- Taking their concerns about their child's development seriously - valuing their experience as a parent and showing them how best to support their child's development. Helping them to find out about their child's special needs or disability and supporting them through the process of assessment and diagnosis. Helping them to access benefits, grants and specialist support.
- Having a few hours off every week (through free or subsidised childcare sessions) to spend time with other children, their partner, or just putting their feet up. Encouragement and where necessary, practical support (e.g. childcare or a taxi) to get them out of the house and joining SSLP and community activities.
- Information and advice on choosing a local setting, liaising with staff and if necessary, statutory agencies. High quality early learning, play and childcare opportunities – with skilled and friendly staff, who work flexibly to include their child. Seeing their child happy, coping well and making friends.

*Source: Discussions with parents in 12 fieldwork SSLPs.*

## 5. Influencing service delivery

SSLPs have also influenced the way local services are delivered to young children with special needs and their families, moving towards a model consistent with the vision set out in *Every Child Matters* and the *National Service Framework*.<sup>40</sup> Five over-arching themes emerge – explored in greater detail in the following chapters (on family support, health and early years services) – but introduced briefly below.

### 1. Raising expectations: 'can-do' attitudes and inclusive services

Every SSLP visited was successful in establishing an inclusive 'value framework' across its own services and in some areas, influencing other providers such as local playgroups and childminders. This was evident in a strong commitment to equal opportunities, with high expectations of inclusive practice underpinned by flexible staffing and funding arrangements and accessible, well equipped facilities.

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<sup>40</sup> HM Government, Sept 2003, *Every Child Matters*; DH/DfES, 2004, *National Service Framework for Children and Young People and Maternity Services*.

## 2. Working on a preventive basis

Most SSLPs employed health specialists – speech and language therapists, mental health outreach workers and less commonly, physiotherapists – to work on a preventive basis, addressing emerging special needs without the need for an assessment or external referral. This tended to involve a combination of work with individual children and their parents, usually through a series of home visits; and wider group activities and courses for parents, family support and early years staff.

## 3. Overcoming barriers to access

Families with children with special needs and disabilities can face more barriers to services than most. Those described by parents interviewed during the research included concerns about reactions to their child's behaviour or appearance, unsuitable buildings and transport difficulties, demands on their time - particularly if their child had many appointments - and language and cultural barriers.

SSLPs have worked creatively to overcome such barriers, principally through their family support services - visiting parents in the home, exploring which services they would like, building their confidence to join in, organising taxis and childcare and undertaking targeted outreach with BME communities. SSLPs have also improved physical access – upgrading community facilities and creating accessible, well equipped centres. Many also funded minor adaptations or the purchase of special toys and equipment to support the inclusion of individual children.

## 4. Joining-up services around children and family.

While the SSLPs visited in this project differed in the range of services developed, all offered an integrated programme of support, including health, family support, early learning, play and care opportunities. Parents appreciated the way SSLP staff worked to 'join-up' services for them: filling gaps in statutory provision, for example, following a diagnosis, discharge from hospital or an assessment; considering the needs of the whole family and helping them to plan ahead; finding an answer to their questions and helping them to access other services.

'Joined-up' working was also a key benefit highlighted by professionals interviewed in most areas. They felt this contributed to improved awareness of special needs and other services; more flexibility in terms of how to respond; more opportunities for seeing the 'whole picture' – looking beyond the presenting need and problem-solving with colleagues; and greater ease and speed of referrals.

However, a few SSLPs operated in fragmented way - with individual teams or specialists working quite separately. In these areas, the 'added value' of bringing services into a SSLP was limited – with little evidence of holistic

responses to family needs, sign-posting across services or joint working to overcome barriers to access or plan ahead.

## **Part two: How SSLPs have improved services for children and families with special needs and disabilities?**

### **2.2 Family support services**

#### **Key messages**

There was a clear link between the availability of family support and how successful SSLPs were at reaching families whose children had more significant needs and disabilities. Family support was valued:

- as a service in its own right - helping parents through crisis periods, building their skills and confidence in supporting their child's development and giving them some respite from their caring responsibilities;
- for providing a 'stepping stone' to enable parents and children to access other services and community resources – providing information, encouraging them to join groups and activities, accompanying them to key appointments, helping them to plan ahead and supporting transitions to nursery or school.

Family support workers play a critical role in joining-up services around children and families, helping to make SSLPs *'more than the sum of their parts'* – responding to families' needs in a holistic way, actively linking with health and early years services.

They also have a significant impact on the success of SSLPs in reaching groups who are less likely to access services themselves – including families with disabled children or children with challenging behaviour, parents with learning difficulties or mental health problems, and families who face language and cultural barriers.

#### **Chapter contents**

1. Overview of family support services in the programmes visited
2. 'Sign-posting' and providing information
3. Developing parenting skills and promoting early child development
4. Moral and emotional support
5. 'Respite' – giving parents a break
6. *'Moving families on'* and supporting informed choices.

## 1. Overview of family support services in the programmes visited

The extent of family support services varied significantly from area to area – reflecting management decisions about the size and skill mix of the team, their role within the local network of services and the needs profile of the population. Across the 12 areas visited, four models were used:

- a small **sign-posting service** – consisting of just one or two people, with no capacity for sustained home-visiting;
- a **small expert team** – variously including a special needs/disability expert, someone with a background in social work, a speech and language therapist, a mental health worker, specialist nursery nurses, housing and benefits advisers and BME outreach workers, usually working with generic family support workers, to provide more sustained and intensive support;
- a **larger generic team** – of ‘home-grown’ parent workers, typically trained to NVQ level 3 in childcare, working closely with in-house specialists (as above);
- **outsourced** family support – from HomeStart, KIDs, Barnados and other voluntary organisations.

Those that were working most successfully with children and families with special needs and disabilities were the small expert team and the larger generic team. These worked well because:

- they were a **core service**, able to work across all aspects of SSLP provision to deliver a coordinated package of support. Outsourced services need to be firmly embedded in programmes if they are to add value in this way;
- they had the **expertise** to provide specialist advice and developmental opportunities to parents and children;
- they had the **capacity** to work with families, sometimes on a sustained basis, to overcome the barriers they face in accessing services – lack of confidence, depression, fear of their child misbehaving and so on;
- they enabled **more effective use of resources**, by allowing for a sensible division of roles between specialist and generalist colleagues.

## 2. ‘Sign-posting’ services and providing information

Family support workers act as a linchpin within Sure Start Local Programmes. They are a key source of **referrals** – ‘signposting’ families to specialist colleagues and encouraging them to join relevant groups and courses.

Family support workers were also active in helping families to **access statutory and voluntary services and providing information** about them. This was particularly significant for families from BME communities, as well as those with literacy and broader learning difficulties. This might involve form-filling, making a phone call, chasing appointments or perhaps organising transport and childcare. A majority said they would take on an advocacy role if necessary.

Parents repeatedly reported that: *“if they don’t know they answer, they know where to find it.”* To this end, most SSLPs had compiled user-friendly service directories and passed on leaflets from local organisations to parents. Information commonly requested by families with children with special needs and disabilities included:

- availability of suitable childcare and early years provision;
- benefits entitlement, particularly disability living allowance;
- local support groups and parent networks;
- the SEN statementing process and more broadly, access to specialist services;
- housing adaptations and re-housing.

Some SSLPs provided information in other BME languages, but a more common approach was to offer support from a family support worker who spoke the same language. In some areas, this extended to accompanying families to key appointments (if they so wished) to ensure that they fully understood the information shared and had the opportunity to ask any questions they wanted to.

Although no SSLP had put in place formal arrangements for ensuring that all families with disabled children had access to a key worker to coordinate services on their behalf, family support workers in almost every area effectively assumed this role – acting as a key point of contact for parents and working flexibly to help them access information and services.<sup>41</sup>

#### **Supporting a family with severely disabled children and language barriers**

One Sure Start, in a poor, 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

<sup>41</sup> The National Service Framework (DH, 2004) expects that all families caring for a disabled child with high levels of need have a key worker. Early Support also promotes the use of the key workers - a pilot of this role was about to begin in one SSLP visited.



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.

### 3. Developing parenting skills and promoting early child development

The principal focus of home visits in nearly all areas was to help parents improve their skills and confidence in supporting their child's development. Typically this involved a short series of visits – 6 weeks being the norm – after which the parent would be encouraged to join a group or course. The focus of such visits varied, depending on the needs of the family and the skill mix of the team:

- Half of the programmes employed **portage** workers, delivering home-based early learning programmes for children with special needs and disabilities (and usually taking on a broader family support role);
- Where the team was made up of generic family support workers, they tended to focus mainly on **parenting skills** and **modelling play** – delivering a variety of programmes such as PEEP;<sup>42</sup>
- Where the team included or collaborated closely with specialist colleagues, they could deliver **specialist programmes**, working on speech and language development, behaviour management, sleep routines, nutrition, continence and in one area, meeting complex healthcare needs;
- Just over half of the programmes **collaborated with social services** to provide hands-on support to families where there were concerns about children's welfare – helping to establish household routines and to ensure that children were properly cared for – including, in five areas, extensive work with parents with learning difficulties.

#### Preventive social work – supporting parents with learning difficulties

One programme seconded a social worker to their outreach team. Jo describes her role as 'old fashioned social work' – helping parents who are struggling to cope with their children to do better for them. Most of her referrals come from social services or health visitors, involving families where there are 'borderline' concerns of abuse or neglect. She works with families –

<sup>42</sup> PEEP is the Peers Early Education Project, an early intervention programme developed in Oxon.

usually on a voluntary basis - for six weeks, before deciding whether statutory involvement may be necessary.

Several cases have involved parents with learning difficulties. One couple, with a severely disabled child, had been referred to social services because they kept missing hospital appointments and appeared to be neglecting their child's health needs. Jo found that they had literacy difficulties and struggled to organise themselves to get to the many appointments scheduled for their child, particularly those out of town. She assumed a key worker type role – setting up a simple calendar system and liaising with other professionals to coordinate appointments. Contact with the London hospital in question led to free transport being provided.

Jo works closely with a nursery nurse on the outreach team, Sarah, who is able to provide more hands-on support to families. Sarah now visits a mother with learning and communication difficulties twice weekly, helping to build her confidence as a parent (following previous involvement with social services) and providing developmental activities for her young son, who has language and behavioural difficulties. The son attends the Sure Start nursery – where Sarah does 1-1 activities with him once a week - and the mother has joined a Sure Start group.

#### 4. 'Moral' and emotional support

Another important function of family support services was to provide **emotional and 'moral' support** to parents, through difficult periods. Sure Start Local Programmes are located in some of England's most deprived communities, where families face multiple pressures associated with low income, poor housing, lack of transport, lack of local amenities and higher levels of drug, alcohol and domestic abuse. Parents whose children have special needs and disabilities can face additional pressures arising from:

- the responsibility of caring for a child who, for example, is in pain or distressed, has no speech, has challenging or unpredictable behaviour, limited mobility or special dietary requirements;
- dealing with painful emotions surrounding their child's needs as well as others' reactions to their appearance or behaviour;
- stretching a low income to pay for special toys, equipment, transport or housing adaptations;
- taking their child to multiple appointments and having to negotiate the complex web of services surrounding disabled children.

Parents valued highly the emotional and moral support provided by family support workers – in particular, knowing they had someone they could talk to when it all got too much. Several parents described their Sure Start Local Programme as being a '*lifeline*'. A critical aspect of this was their involvement in and following 'news-breaking' – filling the gap between diagnosis, sudden illness or injury and service provision. We know from research that news-breaking is a traumatic time for families and that often they feel 'in limbo' – knowing that their child has a condition but not the full implications of what this means. Family support workers in several programmes were helping parents through such periods by:

- accompanying them to key appointments and sitting down afterwards to discuss what had been said, its implications and what to do next. This could be particularly valuable for parents whose first language was not English;
- in one programme, taking on the role of news-breaking and in another, being notified by the paediatrician when a diagnosis was about to be shared (with families' consent) - recognising the strong relationship that they had established with parents;
- more commonly, helping them to find out more about their child's condition and linking them into relevant services and support networks.

#### **Supporting families through crisis periods**

Example 1: 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."*

Example 2: Amina was resettled in a Sure Start area, having had to leave the family home due to domestic violence. This effectively left her as a single Mum, isolated from her family network. Her daughter is disabled and following the move, her younger son's behaviour became 'out of control' and he started running away.

The women's refuge referred her to Sure Start. Through weekly visits, revolving around simple activities such as games, cooking and outings, relationships within the family have gradually been rebuilt. The family support worker has helped them all to talk about their emotions, through drawings and discussions. This, together with advice on sleep routines and behaviour management has helped to turn around the younger son's behaviour. She also helped Amina to find a nursery for her youngest child, to apply for benefits and most importantly, provided emotional support to see the family through a very difficult period. In Amina's words:

*"I'm a lone parent with three children. The most important thing is, if you need to talk about something, to know that you have at least one person that you can say about all your worries, all your problems. You know that somebody's there to help you really out, with information on nearly everything."*

## **5. 'Respite' – giving parents a break**

Access to sessional childcare or 'respite' was a much valued element within the package of family support offered to families with children with special needs or disabilities, in two-thirds of the programmes visited (the others all said they would fund this in times of crisis). Usually, this consisted of just a

few hours every week for parents to spend time with other siblings, catch up on household chores or simply put their feet up. Arrangements varied:

- Just over half the SSLPs funded places in a local nursery or playgroup which could be used flexibly for children with particular needs;
- Several had allocated a flexible childcare budget for purchasing additional provision;
- Two provided regular play sessions for disabled children and siblings;
- There were also a few examples of SSLPs providing flexible childcare in the home – matching families with specialist childminders or offering regular visits by a nursery nurse.

#### **Giving parents a break: access to sessional childcare (or 'respite')**

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.

Marianne lives on the estate with her three young sons. One has a painful physical disability and she has suffered from depression. The family had moved from another area and have yet to establish a social support network. Marianne said that the weekly nursery sessions provided for her disabled son have made a critical difference:

*"They've been funding that and really, I can't see me and my family being a family - my partner and me would probably have split up a long time ago - if it wasn't for [the nursery] ... We would never have coped."*

*"They get so much from [the nursery], so not only do we benefit, they benefit. They're getting ... access to a lot of facilities that maybe we haven't got at home. It's just cheery and the staff are so lovely, you go in they all say hello and it just amazes me."*

#### **6. 'Moving families on' and supporting informed choices**

While family support workers might visit regularly, sometimes even daily, during periods of crisis, a critical part of their role was to help 'move families on', getting parents to a point where they felt they could cope on their own. Every SSLP offered an extensive programme of **groups, drop-ins and courses** which provided a vehicle for helping parents to make the transition from the security of home-visits to coming into the Children's Centre (or other setting) themselves. Family support workers would encourage parents to attend by:

- accompanying them the first time, arranging for another parent to do so or for someone to greet them on arrival;

- arranging transport or childcare, if these presented obstacles to their participation.

Just over half of the SSLPs visited offered **targeted groups** for parents and children with special needs, which could provide a useful ‘stepping stone’ to joining wider activities. These included special parents groups and play sessions for disabled children and targeted groups, many focusing on language development or behaviour management.

Family support workers, across most areas, also played an important role in encouraging parents to think ahead, both in terms of their own aspirations and their child’s education. Many parents who had joined SSLP groups or activities had gone on to become volunteers, with some becoming active members of the parents forum or Board.

**What parents 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’.”

“It’s the confidence they’ve given me. When I first started, I wouldn’t say boo to a goose. But I’ve been on all these courses, I chair the parent-carer meeting.”

Where there was a special needs outreach worker they were also able to play an active role in promoting informed choices and supporting transition to nursery. This is described further in 2.4 Early Learning, Play and Care.

**Part two: How SSLPs have improved services for children and families with special needs and disabilities?**

**2.3 Health services**

**Key messages**

SSLPs have overseen an expansion in specialist health services for young children - in particular speech and language therapy, mental health services and less commonly, physiotherapy.

Health specialists are working with much younger children and critically, offering services on a preventive basis, through:

- home visits to develop parents’ skills in promoting their child’s development and managing their behaviour – often with rapid results;
- awareness-raising and ‘mainstreaming’ effective practice by running groups and courses for parents and training early years and other SSLP staff.

In this way, SSLPs may in time help to reduce the incidence and impact of two of the most prevalent special needs in the communities they serve –

speech and language delay and emotional and behaviour difficulties. Many SSLPs also supported an enhanced service for young children with special needs and disabilities, supplementing statutory provision. Most SSLPs thought that they had reduced demand for specialist services.

Collaboration with family support workers has enabled health specialists in SSLPs to engage more effectively with 'hard to reach' groups – following up on missed appointments, overcoming language and cultural barriers and building parents' confidence about asking for help where it is needed.

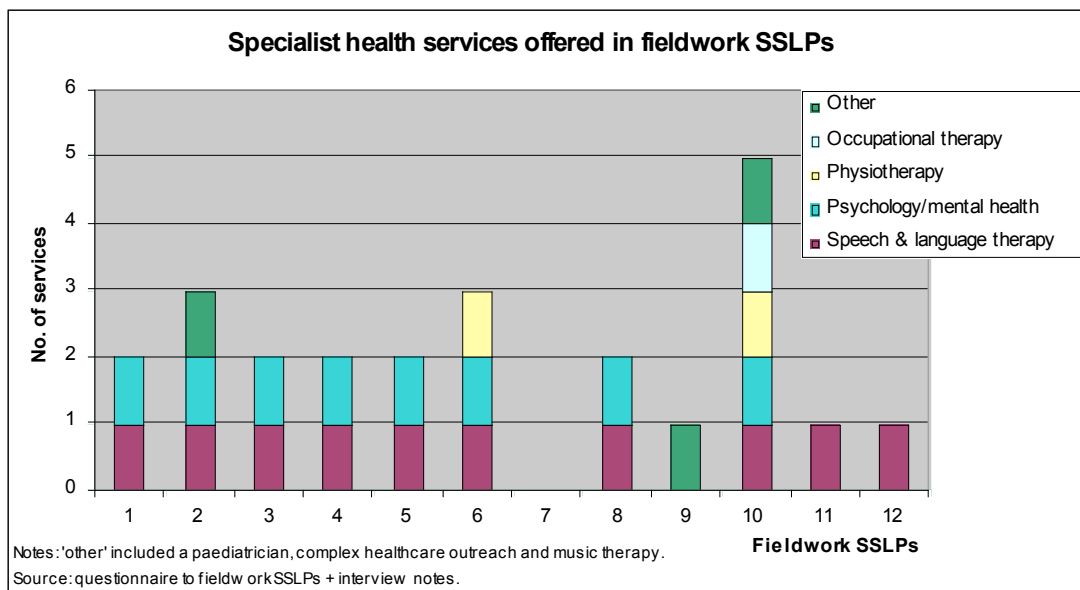
## **Chapter contents**

1. Overview of health services in the programmes visited
2. Raising awareness and skill levels
3. Needs identification
4. Home-visiting
5. Clinics, groups and drop-ins
6. Work with early years settings

### **1. Overview of health services in the programmes visited**

The extent of health services bought-in by Sure Start Local Programmes varied widely - from no specialist services in a programme which focused on public health promotion, to a multi-disciplinary team with a speech and language therapist, physiotherapist, occupational therapist, music therapist, educational psychologist and portage worker [see exhibit].

The most commonly offered services were speech and language therapy and mental health provision. A few programmes provided physiotherapy and one – in an area with an unusually high number of disabled children - provided outreach for children with complex healthcare needs. Nearly all employed midwives and health visitors, some of whom had developed a role in providing enhanced support to children and families with special needs and disabilities – for example, working with mothers experiencing post natal depression and parents with learning difficulties. Several employed nursery nurses to supplement capacity on their health teams.



## 2. Raising awareness and skill levels

Raising awareness of developmental norms and embedding recognised 'good practice' in promoting children's early development was a key element of speech and language therapists' work in most areas visited, and to a lesser extent, mental health workers' and physiotherapists'. Strategies for raising skills and awareness included:

- providing advice and supervision to colleagues - including family support workers, nursery nurses and childcare workers;
- running workshops and short courses for Sure Start colleagues, early years practitioners and parents;
- disseminating simple, clear leaflets, posters and learning materials;
- contributing to the SSLP programme of groups and drop-ins – designing course materials and activities and regularly running sessions themselves.

Many programme managers encouraged specialist staff to be a visible presence and a friendly face, known to parents – by dropping into the café, play sessions or weekend events to meet parents and chat informally. They felt this helped to raise awareness of their service and to lessen the perceived stigma of asking for help. For example, one mother who had been reluctant to seek help for her mental health problems eventually came to the clinical psychologist and said: *"I want to see Martha, not the psychologist!"*

### Raising skills and awareness in speech and language development

Sure Start has established an attractive Children's Centre with a highly inclusive nursery on a deprived estate in the South of England. Local children have above-average levels of speech and language delay and social, emotional and behavioural difficulties. A speech and language therapist, Christine, is based there for two days a week. She regularly visits the six local pre-schools:

- training staff – about developmental norms and common difficulties, how to use song

and rhymes, Makaton, signing and symbols, or how to adapt the room for children with particular needs;

- preparing resources for staff to use and training them in the '*Nursery Narratives*' programme, which uses story-telling to develop children's vocabulary, attention and listening skills. This was incorporated in *Circle Time* in three of the pre-schools and the evaluation showed a very positive impact, including for children thought to have clinically-significant delay.

Christine has collaborated with the clinical psychologist to develop a broader enrichment programme, covering language and behaviour. She has also worked closely with nursery nurses in the Children's Centre, helping them to develop competencies in speech and language development.

Christine does not carry a case load, which has enabled her to focus on preventive work. She does however meet regularly with the area SENCO and clinic-based SLTs to review the caseload across the area and undertakes some direct work:

- following up on missed appointments on behalf of clinic colleagues, working with the pre-schools and outreach workers; and
- joining outreach colleagues on home-visits, providing advice on speech and language development as part of the package of family support.

To reach a larger number of families, she offers two targeted groups, to which parents can sign up or be referred:

- *Baby-signing* is an inclusive group, offered to parents whose children have special needs or others who are interested. About 15 parents come, following a 10-week course which includes singing and signing, parent-child interaction, play activities and so on. Because it is a closed, stable group, it has been successful in engaging less confident parents who have gone on to access other SSLP activities.
- *Toddler Talk* is offered for two year olds at risk of speech and language delay, many referred by health visitors and the nursery. Up to 8 parents (and children) attend for 5 weekly sessions – which include reading stories, singing, craft activities, play, and information on language development. Weekly topics are prepared and parents take away a toy bag, with a book, toys, words and activities to practice during the week. Christine visits them in the home at the outset and again, at the end of the course, to review progress and find out if they would benefit from further support or involvement in other SSLP activities.

### 3. Needs identification

Most health professionals valued the increased scope they had, by working in a SSLP, for identifying emerging special needs at an early opportunity, allowing support to be targeted before difficulties grew and became entrenched. Early years and family support practitioners in most programmes also saw needs identification – and referral to specialist colleagues – as an important element of their role and had been trained to be aware of developmental norms and risk factors. Several programmes had developed screening programmes to ensure a more systematic approach to needs identification:

- to ensure that children's needs were considered holistically by those working most closely with them – usually, health visitors or family support workers; or



- to identify particular needs, such as speech and language delay or physical difficulties, by tracking children at risk or screening children in early years settings [see box below].

Attitudes towards needs identification varied widely across the programmes visited. Some were concerned that identifying needs suggested a deficit approach – fixating on children’s difficulties and ‘labelling’ them, rather than simply working responsively to all needs. However differences in language and culture outweighed differences in practice. Almost all SSLPs adopted an approach consistent with the ‘social model’ of disability – considering what support was necessary to overcome barriers to participation and to promote positive outcomes, rather than seeking to diagnose specific needs and offering clinical responses. Even in those programmes which used screening tools, these seldom resulted in referral to specialist services, but rather, encouragement to join a group or activity, or perhaps the offer of home visits.

Feedback from parents around needs identification was generally positive. Many described how they had concerns about their child’s development, so felt relieved when a professional broached the issue and offered to help – usually through a series of home-visits or perhaps some targeted work in the nursery or crèche. Parents particularly appreciated when professionals sought their views and showed them how to meet their child’s needs more effectively. Where external referral was required, family support workers in several areas provided moral and practical support - some accompanying parents to key appointments, or more commonly, organising taxis or childcare.

**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*.<sup>43</sup> 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, ‘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.

The Programme Manager described the tool as the ‘bedrock’ of their approach – enabling early intervention and the effective targeting of services. It is now being rolled out across the County and piloted in several other areas.

**Early screening programme: Follow-up of low birth weight babies**

<sup>43</sup> Department of Health, 2000, *Framework for the Assessment of Children in Need and their Families*.

One in ten births in the UK are premature. Recent research suggests that eight out of ten babies born before 26 weeks gestation will have an impairment at age six.<sup>44</sup> Low birth weight is associated with increased likelihood of special needs – including cerebral palsy, visual impairment and dyspraxia.

One SSLP was funding an enhanced paediatric physiotherapy service to support the extension of a screening programme for premature and low birth weight babies. All children meeting the criteria (based on birth weight and no. of weeks gestation) are screened at six monthly intervals up to the age of two years, and beyond if concerns are identified. Referrals are also taken from health visitors and nursery nurses. Local waiting lists for physiotherapy have been reduced from several months to 2-3 weeks.

Input depends on the child's needs and is usually provided at home. Parents are shown how to position their baby and given ideas for play, information sheets and a booklet of developmental milestones. The physiotherapist may also work with them in the crèche, nursery or through a SSLP group. Children with more severe needs can access special provision at the Child Development Centre.

The physiotherapy assistant also runs groups to raise awareness of how to promote children's physical development, avoiding risks such as flat heads and spinal problems arising from the excessive use of car seats and pushchairs. A *Babies on the Move* group for mothers with babies up to 3 months encourages parents to play with their children and promote their movement, with simple hand-outs on good practice in terms of positioning, establishing routines, early communication and baby massage. She had also trained some of the nursery staff.

Consistent with research findings, they have found an above-average incidence of special needs, especially dyspraxia - and have been able to support these children's development from a much earlier point. An evaluation with parents was very positive.

#### **4. Home-visiting**

Home-visiting was the main vehicle for targeted work by health professionals in all but one programme (which encouraged families to come to its centre). Short interventions often formed a key element of the package of family support – following referral by a family support worker, who might visit alongside the health professional and who could follow-up with the parents, running through the advice again and modelling activities. The approach used across most SSLPs was a programme of 6 weekly visits to work with parents on aspects of their child's development – exploring concerns, modelling approaches and providing resources such as special toys or books. Progress was reviewed weekly and at the end, parents would be encouraged to join a group or course to develop their skills and confidence further.

Home visits were used in most areas to deliver speech and language programmes and to work on establishing sleep routines, improving behaviour and parent-child interaction more generally. One Sure Start, in an area with a high number of children with complex healthcare needs, provided home visits to help parents to be confident in tube-feeding, administering medication and so on.

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<sup>44</sup> Campbell et al, March 2005, *The National Centre for Early Intervention Feasibility Study*.

Feedback from parents who received home visits was very positive: they felt their concerns had been listened to and were more confident about how they could support their children. Home-visits (as opposed to having to attend a clinic) were particularly valued by families with disabled children – who often had many appointments to deal with and difficulties with using public transport or finding suitable childcare - and those whose children had challenging behaviour or responded badly to the more formal environment of a clinic.

Health professionals valued home visits for:

- improving their understanding of children’s needs, including the impact of their home environment and parenting capacity. This could help them to see beyond the presenting needs and influence their choice of strategy;
- enabling them to reach groups – including some of the most vulnerable – who they would otherwise miss, including:
  - families who face language and cultural barriers to services
  - families who do not keep appointments (‘DNAs’)
  - parents with learning difficulties.

#### **Overcoming barriers to services**

Example 1: Lorraine is a young mother whose 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!”*

*“He used to have really bad tantrums, but now I think because he can communicate better, he’s not so stressed out and getting too mad with himself.”*

*“Before he wouldn’t sleep in this own bed, if he did, he’d wake up all the time, but now he goes to bed at 7 o’ clock and sleeps right through, he settles right down now.”*

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

Example 2: Leila is a BME outreach worker, whose main role is to reach out to Asian families living on a predominantly white, working-class estate. Many are asylum seekers, who have been housed there temporarily.

Leila’s own child has special needs, which were not diagnosed until he started school. She believes there are high levels of undiagnosed needs among the BME population – associated with language and cultural barriers, very low income, a reluctance to use childcare and playgroups – so children are not ‘seen’ until they reach 4 or 5 years – and a lack of confidence among some professionals in identifying special needs in children from BME communities, particularly if English is not their first language.

She works closely with the inclusion worker, making joint visits where she suspects that children may have special needs and giving parents activities they can work on with their children, to support their development. The SSLP also has a flexible childcare fund which can be used to purchase sessions in local settings. Leila uses this to enable fuller observation of some children, working in partnership with the setting. This can throw light on the presenting needs – and how far they relate to the child’s home environment or language barriers – as well as helping parents to accept that their child may benefit from early years provision and specialist input.

## 5. Groups, drop-ins and clinics

Groups, drop-ins and clinics provided an important way of ‘reaching’ more families and sustaining input beyond home-visiting.

All SSLPs offered **universal** groups – open to anyone interested, although staff would generally encourage families towards the most relevant. These tended to be run by health visitors, nursery nurses or childcare workers, with regular input from specialist colleagues – who might have designed elements of the programme and would run occasional sessions. Many had a developmental focus, for example:

- speech and language groups - such as *Happy Babblers*, *Chatterbox*, *Rhyme Time* and *BookStart* sessions;
- adult-child interaction and behaviour management groups - such as *Childhood Matters*, *Growing Together*, *Toddler Praise*, *Managing Behaviour* and *Living with Children*;
- physical development, motor skills and fitness groups - such as *Tumble Tots*, *Jumping Jax*, *Baby Gym*, *Busy Bodies* and *Little Fishes*;
- baby massage (offered in most SSLPs), which some suggested was beneficial for those with attachment difficulties and for babies born prematurely.

Several programmes chose to **target** groups at children and parents with particular needs. These tended to be slightly more structured, with more hands-on involvement by specialists, and parents were expected to commit to attending for the duration. Some felt that these smaller, more stable groups - where every parent was dealing with similar issues – offered a more reassuring environment for less confident parents.

Finally, some SSLPs offered **clinics** - on fairly traditional lines - with a health practitioner making themselves available to see children or parents at a regular time each week or month. For example:

- a mental health worker ran a weekly clinic as a way of managing her caseload;
- one SSLP offered a monthly session for parents to meet a physiotherapist and occupational therapist;
- one Children’s Centre had weekly visits from a paediatrician, giving parents the opportunity to raise any concerns with her;

- there were also many examples of health visitor and midwife clinics.

## 6. Work with Early Years Settings

Health professionals in almost all the programmes visited were providing specialist advice to early years providers. Again, the key services involved were speech and language therapy and mental health, although there were also examples of physiotherapy and complex healthcare outreach. Their involvement included:

- **advice on including children with particular needs** – for example, children with delayed speech, autistic spectrum disorders, poor muscle tone or complex healthcare needs. Health colleagues were also active in arranging for external advice to be provided, if necessary;
- **training early years practitioners** and developing resources for them to use. Speech and language therapists in just over half the programmes visited provided training to early years settings, including Makaton (and other signing systems). Mental health workers in a few areas ran training sessions, but more often behaviour management training was provided by others – such as the special needs lead, a pre-school advisory teacher or the local education authority.
- **observing children in nursery** (with parental consent) to build up a fuller picture of their needs and suggesting strategies for staff to use to support their development. This tended to be at the request of the nursery, but there were also examples of health professionals asking to observe a child in their early years setting, where a longer period of observation was required or the home environment was too disruptive.

## Part two: How SSLPs have improved services for children and families with special needs and disabilities?

### 2.4 Early learning, play and care

#### Key messages

Sure Start Local Programmes have worked to extend and improve early learning, play and childcare opportunities. Of particular relevance to children with special needs and disabilities, they have:

- worked with parents to promote children's early learning and development from birth onwards – through groups, drop-ins and courses and home-learning programmes such as portage;
- expanded the availability of high quality, inclusive early years provision (both 'in-house' and locally) - upgrading buildings and play areas, training staff, buying special toys and equipment and offering specialist

advice and support;

- supported the inclusion of individual children - helping parents to make an informed choice of setting, planning ahead with staff and the family, and providing hands-on support through transitions.

However, there was not a clear link between the extent or quality of early years provision made by SSLPs and how far children with special needs and disabilities were included. While ‘flagship’ nursery provision 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 from other SSLP services, with little information-sharing or collaboration between staff.

## Chapter contents

1. Overview of early years provision (i) in-house (ii) in local settings
2. Developing the skills and capacity of local providers
3. Promoting early learning and development
4. Flexible funding arrangements
5. Improving access: capital developments
6. Supporting informed choices and transitions

### 1 i. Overview of early years provision: in-house

SSLPs varied greatly in terms of the extent of early years provision developed and how far this was considered central to their ‘offer’ to families:

- Several had developed ‘**flagship**’ nursery and daycare provision - with bright new buildings, well equipped facilities and skilled staff. Feedback about their quality and inclusiveness was positive and their reputation attracted children with diverse needs, on the recommendation of local parents and practitioners.
- Most SSLPs offered a **playroom** and **crèche** – in a few areas, this was the extent of their early years provision. These were used to provide play and childcare sessions, loosely based on the *Birth to Three Matters* curriculum. Half of SSLPs visited had created **sensory rooms** and **soft play areas**, suitable for children with special needs and disabilities. These could be significant in drawing in families with disabled children – some invited special groups and individuals to use them, but in others, there were concerns that these expensive facilities were underused.
- Nearly all programmes offered **flexible childcare** for those attending courses or meetings, and most provided **regular ‘respite’ sessions** for

the parents of children with special needs and disabilities – giving them a few hours every week to themselves (see 2.2 Family Support).

- A few programmes supported **special play sessions for disabled children** – at weekends, in the school holidays, and in one area, on several weekday evenings. These successfully included children with significant support needs, as well as offering regular ‘inclusive’ sessions for siblings and other children.
- A small minority of SSLPs had **no early years provision** of their own, but supported an extensive programme of activities in community settings and flexible childcare for those attending courses and meetings. They also funded **portage** for children with special needs and disabilities and were working to increase the availability of **childminders** with expertise in special needs [see box].

#### **Early years development in a rural SSLP**

Early consultation in a dispersed rural SSLP showed that new daycare/nursery provision was unlikely to be sustainable and that local parents wanted services in their own villages - not want a ‘fancy new building’ centrally. The programme used its capital funding to support improvements to local pre-schools and playgrounds, and supported some modest new builds in neighbouring villages.

It funds a **Pre-school Alliance outreach worker** who runs groups and activities to get parents involved in children’s learning (including targeted outreach with the traveller community) and a generous **portage service**, providing fortnightly home visits to about 20 children with special needs and developmental groups.

The SSLP also invested in **childminder development** – recruiting and training childminders to provide early learning in the home and flexible childcare for children with special needs and disabilities. Local training opportunities are offered to those who want to develop their skills in working with children with special needs – including autism awareness, baby signing, behaviour management and speech and language development. They now have 32 childminders on their books, 7 of whom, for example, can work with children with autism and 17 who are able to support children with speech delay or hearing loss.

The childminder development coordinator is a qualified teacher. If a child has special needs (or suspected special needs), she draws up a care plan or differentiated play plan and reviews progress after six weeks. This can lead to referral to the (local authority) Early Years team or area SENCO. She also helps to plan transitions - liaising with local heads and putting together the necessary information.

Social services fund a parallel post across a wider area, also in collaboration with the National Childminding Association, to increase supply of childminders able to provide wrap-around care and short breaks to families in need. The majority of referrals involve children with challenging behaviour or disabilities. Collaboration with the SSLP coordinator enables children to be matched to suitably skilled childminders, with improved access to developmental opportunities and support.

## 1 ii. Overview of early years provision: partnerships with local providers

Just over half of the programmes visited were actively collaborating with local settings to increase the availability of high quality early years provision. This involved:

- **helping new providers to get started** – supporting bids for Nursery Neighbourhood Initiative funding, hosting a private or voluntary nursery on site or building new facilities;
- **support to improve the quality of provision** – upgrading buildings and play areas, training staff and purchasing new toys, equipment and learning resources. Half of the programmes visited had supported major capital upgrades - adding new rooms and play areas - while a few had been active in 'turning around' failing providers;
- **using local settings as 'satellites'** for delivering SSLP services, in several areas - such as health clinics, drop-ins and courses. This helped to improve their 'reach' in pockets of the community, as well as facilitating joined-up working between local settings and the SSLP.

## 2. Developing the skills and capacity of local providers

Two-thirds of the programmes visited were working with local providers to raise awareness of special needs and disabilities and to support the inclusion of individual children. The key vehicles for this were:

- **staff training** to raise awareness and build staff confidence in responding to special needs and to recognise when a referral may be appropriate. This tended to be provided by the special needs expert on the outreach team (where there was one), the speech and language therapist, or less commonly, the mental health worker or physiotherapist. In several programmes, the special needs expert was also a pre-school advisory teacher or an area SENCO, providing a valuable entrée for the SSLP to develop relationship with local settings.
- **specialist outreach** to support the inclusion of individual children. Again, this tended to involve the special needs expert, speech and language therapist, mental health workers or physiotherapists. In a few areas, portage workers supported transitions to nursery and one SSLP provided specialist outreach to support the inclusion of children with complex healthcare needs.
- **on-going access to advice and support** – through phone contact with SSLP specialists and in some areas, regular visits by them. Early years staff in most areas reported that access to external advice had become easier as SSLP colleagues had better knowledge of – and contacts in – partner agencies.



However, some SSLPs did not collaborate with local providers around children with special needs and disabilities, although they would have been well placed to do so – given the facilities they had and the skills of their staff. While they were meeting children’s needs successfully in their own provision, they were unable to support children whose parents chose another setting.

Overall, early years provision was the least well embedded of SSLP services – particularly where high quality nursery or daycare provision pre-dated the SSLP and had been allowed to continue operating ‘at arms length’. This undermined the potential for sensitive forward planning, supported transitions, holistic responses to individual needs and specialist outreach and professional development opportunities.

#### **Developing speech and language skills in early years settings**

A speech and language therapist in a London SSLP with an ethnically diverse population works extensively with early years settings – raising awareness of developmental norms, training staff, modelling activities and providing learning resources. This has included:

- visiting all local settings on a monthly basis, to chat informally with staff and parents and leave a “Top Tip” (printed on a poster) for them to work on – such as sharing a book or reducing distractions;
- making regular visits to demonstrate small group activities which promote language development and providing laminated materials for staff to use;
- developing a simple screening tool (initially for use with bilingual children) to throw light on children’s needs. Staff are trained in its use by working alongside the speech and language therapist and being observed by her. Feedback has been positive - particularly in terms of raising awareness of more subtle needs such as social communication and comprehension difficulties. The tool has not resulted in many more referrals, but where these are needed, they have better information to support them.

### **3. Promoting early learning and development**

The expansion in early learning, play and childcare provision was considered particularly significant in terms of extending opportunities for children under 3 years of age (and therefore not entitled to free nursery education), given the fact that many families in SSLP neighbourhoods live on a low income. SSLPs have also worked to help parents to support their child’s early learning and development before they even join a local setting, by offering:

- **home-based learning** through their family support teams – including portage, play programmes and targeted specialist programmes to support language development, behaviour management and so on (see 2.2 Family Support);
- **groups & drop-ins with strong developmental component** – such as parenting skills, speech and language development, behaviour management (see 2.3 Health chapter – and box below).

#### **Extra developmental opportunities for children with special needs**

About one-third of the children attending a SSLP nursery on a run-down urban estate are reckoned to have special needs. The community historically had little access to early years provision and was bounded by busy roads. 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 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.

#### **4. Flexible funding arrangements**

Many programmes had developed flexible funding arrangements to support the inclusion of children with special needs and disabilities, often offering an enhanced entitlement to free childcare and play sessions. Arrangements included:

- **flexible budgets** – in about half of the programmes, to buy special toys or equipment and occasionally to provide short-term support, while longer-term arrangements were put in place;
- **resourced places** – again, about half the programmes funded a number of places in their own or local settings, for children with additional needs. These could be used flexibly to provide additional sessions for children and respite for parents, as part of the package of family support;
- **'respite' childcare** – all indicated that they would be prepared to fund short-term sessional childcare for children with special needs and disabilities to help families through crisis periods, with most providing weekly sessions.

## 5. Improving access: capital developments

SSLPs have used their capital funding to improve the accessibility of in-house and local early years provision in a variety of ways. Half had supported **major capital upgrades**, building new rooms, play areas and sensory rooms, and half described how they had supported **'reasonable adjustments'**, as required by the DDA 1995. Examples included:

- installing accessible toilets, ramps, a lift, hoists, larger changing areas;
- removing a step and adding high-visibility strips;
- buying large font books, adjustable furniture and equipment, special toys and mobility devices;
- creating soft play areas for children with fragile bones or poor muscle tone;
- rearranging room layout.

Encouragingly, physical access was not a barrier in all but a small minority of programmes - in crowded urban areas, where the SSLPs operated largely on an outreach basis, using a variety of buildings owned by partner agencies; and in an rural area, where all services were delivered through local providers working in villages.

## 5. Supporting informed choices and transitions

Many SSLPs were working proactively to encourage parents to let their child join an early years setting, helping them to choose the right one and providing hands-on support through the period of transition. This involved collaboration between early years and family support workers and sometimes also health professionals.

### Early years outreach

In several areas, early years staff offered home visits to all children due to start nursery. One also supported children joining reception class (they were co-located with a school) – with their learning mentor accompanying parents on a visit to the school, taking photos they could look at during the summer holidays and visiting children regularly during their first term. Another invited staff from feeder nurseries to join their weekly sessions for children with special needs and disabilities.

More commonly, parents and children were offered advance visits or 'taster sessions' to familiarise them with the new setting. One programme invited all children starting nursery to attend weekly play sessions, letting them get to know staff and the new environment and making staff aware of potential special needs. Another had developed a six-week '*Welcome to Nursery*' course, hosted in local settings – exploring children's feeling on transition to nursery, how parents would feel, the foundation curriculum and so on.

Numerous examples were given of the way in which settings worked flexibly to help children to settle in – allowing them to build up their hours until they felt comfortable following the same routine as other children.

### Family support outreach

Family support workers in the majority of programmes played a role in helping parents to choose an early years setting and working flexibly to prepare the family and staff. In some cases, this involved extensive liaison – bringing in specialist advice from health colleagues, arranging for the purchase of special toys or equipment or even providing a learning assistant for a limited period.

Special needs and disability outreach workers felt they played an important role in ‘supporting informed choices’ and challenging assumptions about what was possible. This was echoed in feedback from parents, several of whom said that they had kept their child at home because they were worried about their behaviour, or that the playgroup or nursery would not be able to meet their needs, or that it would cost too much ... or a variety of other reasons! Outreach workers had given them information on what was available, helped with form-filling where needed and sometimes accompanied them on visits. Portage workers were involved on a similar basis.

A few family support teams also provided support in the nursery beyond transition – with staff accompanying the child to their new setting and spending time with them until they settled in.

### Transition beyond SSLP services

Support for transition beyond SSLP services – to school and for some, statutory provision to meet their special needs – remained an area for development in nearly all the SSLPs visited. Few had forged relationships with local schools, even when they were co-located. Parents in several areas expressed concerns about what they would do when their child was no longer eligible for SSLP provision, anticipating that they would just have ‘to start again’.

#### **Working flexibly to include one little boy**

Adam is a bright child with more energy than most. He has a hearing impairment, delayed language and behavioural difficulties, for which he has a statement of special educational needs. Aged 2, he was excluded from a private nursery for kicking and biting other children. His parents both worked full-time and did not know where to turn. A staff member suggested they try the Sure Start nursery, as it had a good reputation for including children with special needs.

The Sure Start nursery immediately accepted Adam and worked flexibly to help him settle in. They changed the room layout – so that he wasn’t near the younger children, whom he was more likely to trouble – and arranged for him to have the same staff working with him, as far as possible. He initially struggled to cope with full day sessions, so they suggested he attend part-time and adjusted their timetable to match his Dad’s working hours. As Adam settled in and made new friends, they gradually they built his hours back up – and sometimes he now stays for their extended provision!

Adam is now 4 years old, so he will soon be moving on to reception class at a local primary school. His parents knew which school they wanted and the Sure Start nursery liaised with staff there to plan his transition. New entrants are normally invited to spend some time at the school before they start, but for Adam, his new teacher and learning support assistant will first attend the Sure Start nursery for a day or two, to get to know him.

Adam's Dad highlighted two things he liked best about the Sure Start nursery. First was the support Adam has had and more generally, the quality of provision – which he described as '99% perfect'. Just as important were the staff attitudes - immediately accepting and always friendly. In his words:

*"You know, it's very hard to ban a child from biting. They understood it, they saw it as normal behaviour and gradually ... it changed."*

*"Everyone's all so friendly – you don't feel like they're work people, they're just like friends now ... they're very professional about their job but they're ... human is the word, I suppose!"*

## **Part three: What works? Learning from local practice**

This section describes aspects of SSLP strategy, management and operations which were associated with effective practice in working with children and families with special and disabilities, across the twelve programmes visited. It concludes with a summary checklist for managers.

### **Contents**

- 3.1 Leadership, consultation and governance
- 3.2 Registrations, referrals and reporting
- 3.3 Joining-up services
- 3.4 People and skills
- 3.5 Employment, management and supervision
- 3.6 Information systems
- 3.7 Monitoring and value for money
- 3.8 Funding arrangements
- 3.9 'Fit' with local services and sustainability
- 3.10 Checklist of effective practice

### **3.1 Leadership, consultation and governance**

All the SSLPs visited had inclusive policies and were working responsively with children and families with additional needs. However, programme managers varied in their awareness of special needs and disabilities and in their perception of how far their services were relevant to those with more complex and enduring needs. Programme managers were, unsurprisingly, the key influence on how far local programmes sought to tailor services for this group and in turn, on how well they reached them.

Several programme managers had experience (as a parent or professional) of special needs and disabilities and this contributed to a higher profile within the programme. Senior managers also exerted an important influence – in

particular, outreach/family support managers – many of whom had a background in special needs and disabilities. By contrast, in the few programmes which had little involvement with disabled children, senior managers suggested that:

- these children were already well served by statutory agencies or voluntary organisations;
- they probably would not want to use SSLP services (even though all had well equipped play areas and sensory rooms);
- there were not any such children locally.

Programme managers need to have children and families with special needs and disabilities ‘on their radar’ and build awareness of this group into all aspects of practice - from staff induction through to monitoring and review arrangements. A clear commitment to inclusion in SSLP policies, literature and publicity – together with positive stories and images - can help do much to reassure those who might otherwise stay away.

#### **Reaching out to families with disabled children**

A SSLP in a deprived former industrial area with an 80% Asian (predominantly Muslim) population works extensively with children with severe and complex needs. This reflects the needs profile in the community - characterised by high levels of disability, neurological and degenerative conditions – as well as the priority attached to children and families with special needs and disability in this programme.

Family support is the main service offered. The team includes two former nursery nurses with a background in working with children with disabilities and complex needs. When the first one joined – six months after the SSLP was established – there were no such children on their books. They currently support over 100 children with special needs or disabilities, most of whom have a diagnosis. Local community and CDC health visitors spoke highly of their expertise – including complex healthcare, continence, sleep management, behaviour management, dietary advice and portage.

The outreach team is representative of local community, speaking many different languages and dialects. Parents met during the visit valued having someone who could speak their own language and the help they received in being accompanied to appointments, running through doctors’ advice, making phone calls, writing letters and form-filling. The CDC health visitor reported that appointment attendance rates, particularly for BME families, had improved significantly.

Other aspects of practice which may have helped this SSLP to reach families with disabled children well were:

- a clear commitment to inclusive practice in all their literature and publicity, with positive imagery, case studies of how they had worked with disabled children and practical information on e.g. the accessibility of the local zoo;
- inclusive holiday play schemes and a Saturday club, able to include children with high support needs and siblings;
- support for special parents groups, providing crèche facilities;
- strong links with local CDC and family centre.

On the downside, this programme was held back by a lack of building – operating from a variety of venues, some with poor access. A new Children’s Centre was due to open soon, including a nursery with 6 resourced places for children with complex needs.

## Finding out what parents want

A range of approaches had been used to explore what families with special needs and disabilities wanted, in terms of service provision:

- early '**mapping**' **exercises** (of the needs of the local population), influencing decisions about which services to invest in;
- special **parents working groups**, some in partnership with voluntary organisations, had helped to shape services in several SSLPs, while **targeted consultations** had informed subsequent service reviews – highlighting continued barriers to access;
- **learning from others' consultations** and/or evaluations – for example, joining CDC or voluntary organisation events and developing services to fill the gaps already identified by others.

### Consulting families with children with special needs and disabilities

Only two of the twelve SSLPs visited had evaluated the experience of families with children with special needs and disabilities. The themes emerging from their evaluations were very similar - and are summarised below. Parents valued highly:

- regular home-visits - both SSLPs employed outreach workers with expertise in special needs;
- access to childcare, early years provision and play sessions, with supported transitions.

Outreach workers had given many parents the confidence to join 'mainstream' SSLP activities. But some still felt they faced barriers to access, including:

- concerns about inaccessible buildings, if they would be made to feel welcome and be able to join in properly;
- language and cultural barriers;
- confidence and practical difficulties - some had highly complex needs, beyond their child's special needs or disability.

Parents also wanted:

- special groups and play sessions for parents and children with special needs and disabilities – feeling they would be more confident about joining these;
- more information on special needs and disabilities, displayed prominently and readily accessible;
- for Sure Start buildings and all staff to be more welcoming to children and families with special needs and disabilities – with welcoming policies, positive images and training for all staff.

*Source: local evaluations in two fieldwork SSLPs.*

## Partnership boards

In most areas visited, the influence of the Board seemed limited, although they had clearly played a role in shaping services in the early years of the programme. Most SSLPs had representatives – parents and/or voluntary organisations – with particular experience of special needs and disabilities on

the Partnership Board or Parents Forum. However, only one appeared to have exerted a broad strategic influence. It was more common for them to influence a particular aspect of provision, such as a service they were commissioned to run or a group they were instrumental in setting up. The involvement of agency inclusion/special needs/disability officers on Partnership Boards appeared to have been more influential in shaping services and their 'fit' with local provision - for example, leading to the creation of a small fund to purchase disability equipment or home visits for vulnerable families falling short of social services' eligibility criteria.

### **3.2 Registrations, referrals and reporting**

SSLPs make contact with families in two ways: registrations of new births and families moving into area, and referrals of families with young children who might benefit from SSLP services. Both influence how well they 'reach' children and families with special needs and disabilities.

#### **Registrations**

Some SSLPs knew their population well and were confident of 'reaching' nearly all families, including those with special needs or disabilities. Three factors were significant in enabling this:

- regular updates from partner agencies, in particular, lists of births from the PCT. This tended to work best where the SSLP was health-led or had a senior manager seconded from the PCT;
- good relationships with health visitors, midwives and general practitioners – working in partnership to register new families and make referrals for SSLP services;
- robust information systems, enabling them to track their involvement with families and to know which families were using which services. The basis for recording special needs varied greatly, leading to widely different numbers being reported and little confidence in their validity [see box below].

#### **Referrals**

Those programmes which were working more extensively with children and families with significant needs or disabilities had often first come into contact with them through a referral made by a local agency or voluntary organisation. Referrals were more likely – and therefore 'reach' was better - if the programme:

- had a senior staff member with expertise in special needs and disabilities;
- offered an extensive family support service, particularly if the outreach team included workers with specialist expertise such as speech and language therapy, mental health outreach and portage;



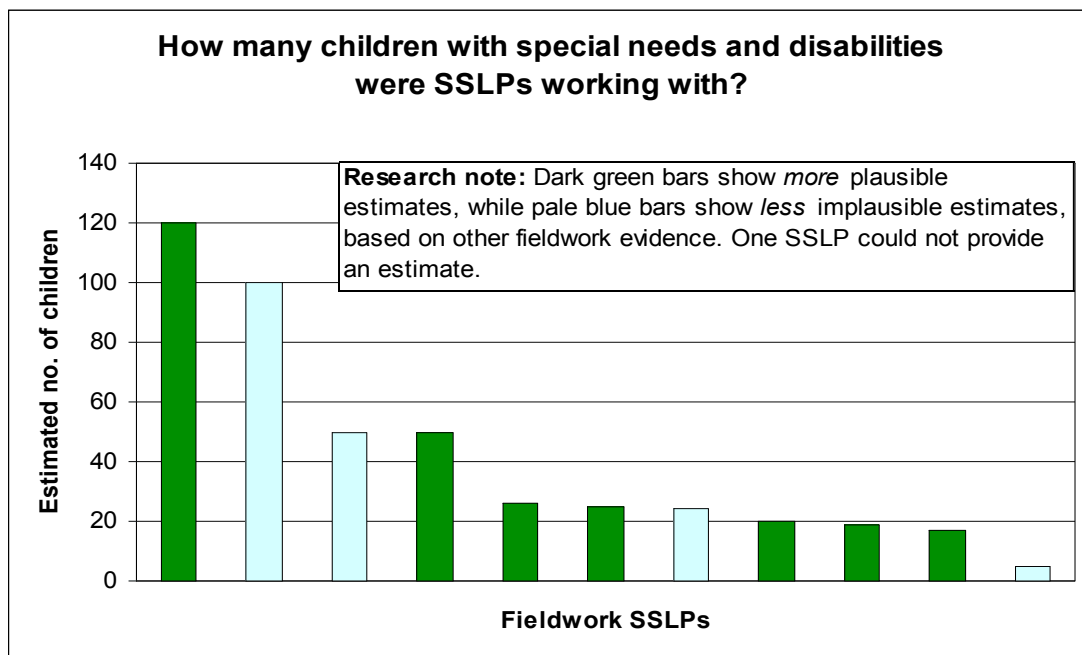
- offered early years provision which was recognised locally for being inclusive;
- offered targeted provision – such as portage, a special parents group, special play sessions or access to special play areas such as a sensory room;
- had established a strong working relationship with the Children Development Unit or Family Centre or, to a lesser extent, the area SENCO.

### Recording and reporting ‘special needs’ numbers

Every SSLP visited was asked how many children with special needs and disabilities they worked with. Answers ranged from 5 to 120 (with an average of 41), but this reflected how they recorded special needs and disabilities more than how many such children they were working with:

- over-reporting was associated with counting service use or any support needs as special needs, regardless of length or intensity of involvement;
- under-reporting was associated with counting those using a key service such as portage, but omitting others such as speech and language therapy or special play.

The table below shows their responses, based on questionnaires filled in by 9 SSLPs, or where these were not provided, estimates given in interviews. The bars are shaded to show which estimates were considered plausible, based on other fieldwork evidence – such as numbers using key services.



### 3.3 Joining-up services

The extent to which SSLPs operated as an integrated programme of support was absolutely central to their effectiveness in working with children and families with special needs and disabilities. While joint working between family support and health colleagues was well established in most areas – with staff often sharing offices and forming part of an extended outreach team – links with early years providers were under-developed in several areas. A key barrier was separate leadership, particularly where ‘flagship’ early years provision pre-dated the SSLP. This was also an issue for some commissioned services, particularly those based externally.

Most SSLPs – including a dispersed rural programme - worked creatively to overcome such barriers, creating flexible office space, scheduling regular staff meetings and providing social opportunities. Factors underpinning effective joined-up working included:

- strong leadership – with clear expectations about the need work flexibly across services reflected in all aspects of practice, from recruitment through performance management arrangements;
- co-locating staff – to facilitate information-sharing, discussion and learning opportunities - and services, for example, running health clinics or parents groups from early years settings;
- creating cross-cutting roles, where working across services was an integral part of the job;
- providing joint training sessions, the opportunity to shadow colleagues in other service areas and induction packages encompassing all aspects of SSLP provision;
- creating unified information systems to underpin holistic planning and review and forums for discussion;
- shared social opportunities – co-running events and outings, eating together, sharing a staff room.

However some SSLP services operated quite separately, thereby missing the potential ‘added value’ of an integrated approach for children and families with special needs and disabilities - such as improved reach, forward planning, supported transitions and holistic responses to families’ needs. Barriers to multi-agency working observed included:

- staff being based at different sites for all or most of the week or working to incompatible timetables;
- weak management and accountability arrangements - particularly for staff based at other agencies, some of whom were under pressure to prioritise agency caseloads over their SSLP responsibilities;

- a presumption against information-sharing, with senior management discouraging staff from discussing cases, patchy record-keeping and no forum for discussing and reviewing practice;
- inherited and differences in language and culture, perpetuated by separate working practices.

#### Overcoming fragmented practice

One SSLP was established about the same time as an Early Excellence Centre, with which it was co-located. Two managers were appointed - with separate entrances to the building, separate staff rooms and different uniforms. Culturally, staff described a 'glass wall' between the early years provision and other SSLP services, including family support, health and parenting. Nursery staff regretted that they had not been able to take advantage of the 'rich wrap-around services' available in the SSLP. Concerns were expressed about a lack of information-sharing, especially around child protection issues. However some staff had successfully worked across both sides, including a learning mentor who was based in the nursery and home-visited vulnerable families.

Recent restructuring had led to unified management, which staff were optimistic about. A shared information system had been set up, together with a system for logging concerns about risks to children's welfare. The former SENCO had joined the senior management team and was developing a cross-cutting role, overseeing work with children with special needs across the programme and professional development opportunities. Staff joining the nursery now shadow SSLP colleagues during their induction period, so that they know who does what and the full range of services available.

### 3.4 People and skills

Another important influence on how well SSLPs were working with children and families with special needs and disabilities was the presence of an **in-house expert**.<sup>45</sup> Half the programmes visited employed a staff member with expertise in special needs and disabilities, typically:

- in a cross-cutting role - often based on the family support/outreach team but working with colleagues across the programme and in partner agencies;
- undertaking some direct work with families with more complex needs;
- advising others on approaches and resources to use, providing some supervision and training opportunities;
- liaising with early years providers to support informed choices and planned transitions [This role is described further at 2.1 Approaches to special needs].

Several of 'special needs experts' were senior staff members, on the management team and able to influence strategic priorities and SSLP-wide practice. These programmes were amongst the most successful in working with children and families with special needs and disabilities. They had developed strong relationships with partner agencies and were known locally for their expertise in this area.

<sup>45</sup> This role is described in greater depth in Chapter 2: approaches to special needs.

It is worth noting briefly that a small number of programmes which did not have anyone playing a lead role on special needs were nonetheless working well with this group. This may be explained by the fact that they had:

- a programme manager who took a keen interest in special needs and disabilities or senior managers with extensive experience in this area;
- information systems that enabled them to be confident about 'reach' and patterns of service use by different groups.

### **Staff skills**

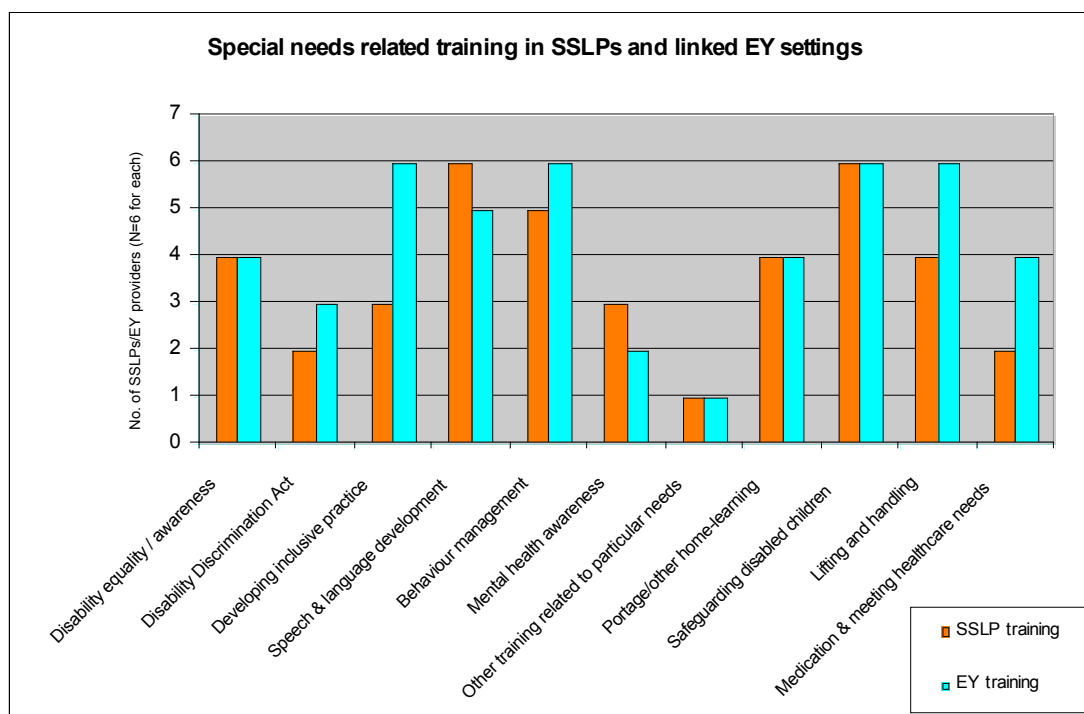
Staff skills and awareness provide an essential foundation to work with children and families with special needs and disabilities. Because SSLPs are integrated programmes of support – with wide-ranging of expertise in-house and in most areas, ready access to specialist training from partner agencies – they are well placed to develop staff skills. Approaches described in the programmes visited included:

- workshops and training opportunities provided by specialist staff to raise awareness of developmental norms, model effective practice and reflect on individual cases;
- co-working by specialists and generalists – making joint visits, running groups and courses together – to share the caseload and build up expertise, for example, enabling nursery nurses to develop their skills in speech and language therapy;
- inviting partner organisations – variously the local CDC, family centre or a voluntary organisation - to run sessions to raise awareness of children and families with special needs and disabilities; taking part in their events and inviting them to participate in SSLP events; and arranging for staff to spend time with them during their induction.

Skill levels in early years services (within SSLPs and those working in close partnership with them) were generally good. Just over half the SSLPs visited had nurseries which prided themselves on being 'centres of excellence', placing great emphasis on the professional development of their staff. The rest offered more informal play and crèche facilities or relied on local providers.

We asked both SSLP and early years managers what special needs and disability-related training their staff had received, over the last two years. Half completed the questionnaire [see table below]. Their responses suggest that SSLPs' access to training was, to some extent, determined by their relationships with key agencies. Where there was a strong relationship with the local education authority, they were mentioned as a key source of training. Where relationships with the PCT were stronger, they tended to be a more important source – and where the SSLP worked closely with a voluntary

organisation, they had often provided development opportunities for both SSLP and early years staff.



Source: Questionnaire completed by 6 managers in fieldwork SSLPs and 6 in early years settings within or working closely with a SSLP.

Most SSLPs benefited from having early years supervisors/managers/heads who were highly experienced and who were known locally for their inclusive practice. All the settings visited had a SENCO, who tended to be a fairly junior staff member who led on preparing IEPs, organising reviews and so on – while others played a more active role in overseeing and advising on work with children with special needs, in particular:

- the setting manager or head;
- the SSLP special needs lead;
- in-house specialists, particularly the speech and language therapist;
- advisory teachers and area SENCOs.

Most SSLP nurseries operated a key worker<sup>46</sup> (or similar) system, giving parents a regular point of contact. Key workers played an important role - in collaboration with the SENCO – observing children and keeping detailed records of the progress they were making and setting targets. In one programme, a learning mentor liaised extensively with vulnerable families, playing a similar role to family support workers elsewhere.

<sup>46</sup> ‘Keyworker’ was the term used in several SSLPs to describe this role; it should be noted that this does not imply that these staff took on a wider coordination role, across SSLP and other services – rather, they were a key point of contact within the nursery/early years setting. Family support workers in most SSLPs played a broader keyworker type role – although no SSLP had formalised arrangements for this.

Factors which had held back progress in building the skills of staff in early years settings to work with children with special needs and disabilities included:

- staff turnover – with several SSLPs lamenting the difficulty they had in retaining the staff they had trained up;
- tensions between the nursery manager and programme manager, limiting SSLP involvement in early years development and specialist outreach.

### **3.5 Employment, management and supervision**

A wide range of employment arrangements for health and family support workers was used across the programmes visited. The most effective involved seconded staff being based at the SSLP for most of the week, but spending one or two days back in their home agency. This worked best where they shared the same catchment area and were able to use the experience gained by being part of Sure Start back in their home agency – for example, leading on work with vulnerable families. Having ‘a foot in each camp’ facilitated:

- information-sharing;
- fast and appropriate referrals;
- better awareness of SSLP resources – such as family support services, expertise in engaging with minority communities, advice and information services – to which agency staff could refer families;
- the development of complementary roles – for example, with SSLP staff following up on missed appointments or working with children falling below thresholds for statutory provision.

By contrast, less successful employment arrangements involved staff:

- being based in their home agency most of the time and largely unaccountable to the SSLP;
- carrying a large caseload, limiting scope for developing preventive work or co-working with SSLP colleagues;
- providing a ‘stand-alone’ service, rather than forming part of an integrated package of support.

Several programmes had developed partnerships with voluntary organisations to provide more sustained support to certain families, including those with children with special needs and disabilities – funding specialist family support workers to visit families with disabled children or an enhanced ‘HomeStart’ service. Although families were positive about the support they received, this appeared to be a less successful model due to:

- concerns that needier families were ‘dumped’ with the external service;
- less ownership by the SSLP of such families, including some of the most complex cases;
- weaker links with other Sure Start services and concerns about dependency.

By contrast, one SSLP had seconded a disability expert from a voluntary organisation to their outreach team, who was a key staff member – advising and training colleagues and influencing SSLP practice more broadly - which seemed a more successful approach.

Many seconded staff raised the issue of management and supervision during their interviews with the research team. They were most positive where:

- consideration had been given by managers on both sides to ensure coherent, non-duplicative management and supervision;
- they continued to receive professional supervision and development opportunities from their parent agency;
- they were line managed within the SSLP, with meaningful opportunities to discuss and review practice.

Management and supervision was particularly important to staff making home visits, helping to ensure that practice was safe and effective, to manage their caseloads and to maintain a focus on '*moving families on*'. Working with vulnerable families, in their homes, can be highly pressurised and staff in more than one area suggested that a lack of supervision contributed to high staff turnover.

Some programmes had developed systems to provide regular supervision for home visitors, using senior colleagues to review cases, challenge assumptions and suggest alternative strategies and resources. Colleagues with a background in social work or psychology were particularly valued in this role.

#### **Management and supervision of outreach workers**

One of the SSLPs visited had an outreach team made up of health and social care specialists seconded from partner agencies for most of the week, together with a number of generic family support workers.

Senior staff are line-managed by the team manager, Anna, with professional/clinical supervision provided by their home agency or bought-in. They in turn manage the generic outreach workers – through regular chats and monthly meetings to discuss and review cases, and to consider development needs. Staff also have the opportunity to seek advice from the wider team by bringing cases to a regular forum, facilitated by Anna, and also involving the senior health visitor, mental health worker and social worker.

The team operates as a needs-led service, with open referrals. On receiving a referral, Anna and/or the relevant worker meet the family to identify the purpose of their involvement and draw up an informal plan. Home visits (if offered) seldom continue beyond 6-8 weeks, as the SSLP encourages families to make use of the extensive programme of groups, activities and courses on offer.

Many of the team carry large caseloads. All highlighted Anna's role in helping to make this manageable: keeping an eye on workloads, exploring alternative approaches when there is too much to do (e.g. starting new groups or co-working with a nursery nurse) and challenging involvement when cases run on.

### **3.6 Information systems**

## Case records

Arrangements for keeping case records varied widely – reflecting different interpretations of the legislative constraints on information-sharing and cultural differences. A presumption in favour of information-sharing, with parental consent, was a contributory factor to successful joined-up working, problem-solving and risk awareness. The systems that appeared most effective incorporated three elements:

- **a high level record of contacts** with the family (usually electronic) both in terms of direct work with them and attendance at groups and drop-ins, including:
  - dates
  - which professionals were involved
  - brief details on content or purpose
  - key characteristics of the family, so that patterns of service use can be reviewed. The basis for recording special needs and/or disability remained a challenge in most areas.
  
- **cumulative case records**, to which all staff working with the family contributed.<sup>47</sup> These tended to be paper-based and usually access was restricted to key staff, for example, to help with planning or reviewing complex cases, or reviewing service use by key groups. Families need to consent to their information being kept and shared in this way. Examples included:
  - adding pages to health visitor ‘baby books’ or ‘red books’;
  - family files, which colleagues add to progressively. In one programme, family files were colour coded to indicate which families were more vulnerable;
  - a rolling electronic case file, with restricted access to certain sections.
  
- in line with the recommendations of the Laming Inquiry into the death of Victoria Climbié<sup>48</sup> **a system for logging concerns about risks to children’s welfare** – such as bruises, a sudden deterioration in health or non-attendance - to allow risk factors to be connected and a decision taken about the need for follow-up action. This had led to child protection referrals and decisions to carry out a ‘CAF’ (common assessment framework), leading to more structured and sustained involvement.

## Collective review

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<sup>47</sup> Health staff, particularly mental health workers, also kept their own detailed case notes, sometimes in their home agency.

<sup>48</sup> *The Victoria Climbié Inquiry – Report of an Inquiry by Lord Laming*, HMSO, January 2003.



Nearly half the programmes had established forums to enable colleagues to discuss cases – almost always with families’ consent<sup>49</sup> - to contribute to effective and safe practice. Examples included:

- a monthly forum for reviewing cases of children with additional needs, facilitated by an inclusion worker, who would follow-up on actions agreed;
- fortnightly case review meetings, chaired by a clinical psychologist, to review practice and reflect on next steps;
- fortnightly ‘family forums’ chaired by a social worker – again, to review practice and seek others’ perspective on the family’s needs and what strategies to use.

In several areas, the absence of a unified information systems or forums for discussion mitigated against forward planning and coordinated approaches to meeting children and families’ needs. For example, several SSLPs relied unduly on the encyclopaedic knowledge of a few individuals – which was problematic, as people move on, taking their knowledge with them and because they are unlikely to provide a full or impartial overview. A newly-joined clinical psychologist in one such area reported that she neither knew if colleagues had worked with families before nor the risks she might face in making a home visit.

#### **Information-sharing in one SSLP**

The family support manager of a trailblazer SSLP saw the need for a more systematic approach to information-sharing and problem-solving in the first few months’ of operation: as team manager and as a former social worker, she tended to be the first point of call for information and advice on work with families. Working with colleagues, she developed a system of ‘family files’ used across the SSLP and a ‘family forum’ for collective discussion and review.

**Family files:** Paper files are kept for each family registered. These include standard information on the family’s circumstances, known risk factors and a case history, with detailed notes contributed by staff members. Families consent to information being kept in this way. One page is set aside for confidential notes, to which access is restricted. A simple system of colour coding is used to denote risk: for example, red files indicate child protection concerns. The SSLP also invested in a database which records all contacts with families, updated using hand-held devices.

Most staff valued the family files – for example, the two inclusion workers said that they were a rich source of information for planning their work with families. However, a few staff expressed concerns about confidentiality.

**Family forum:** The family support manager chairs a fortnightly forum, to which all staff working with families can bring cases. A wide range of staff attend – including counsellors, outreach workers, health visitors, playroom and crèche workers. A laminated sheet of ground-rules is circulated to all attending, explaining the legislative constraints on information-sharing and equally, the imperative to do so where there are concerns about risks to children’s welfare. Consent is normally sought from the family and the discussion remains confidential

<sup>49</sup> Serious welfare concerns may override the need to gain consent. See DH, 2003, *What to do if you’re worried a child is being abused*.

and unminuted. However, the family support manager will record any actions agreed on the family's file.

Feedback on the forum was very positive, although some staff said they struggled to make time to attend regularly. It was valued for providing the opportunity to explore concerns, to seek fresh perspectives on what might be going on and to generate ideas about what to do next. Importantly, the forum allows risk factors to be connected and had led to some child protection referrals.

### 3.7 Monitoring and value for money

#### Monitoring

Monitoring service use and outcomes was an area of weakness in most programmes – particularly in respect of commissioned services. Many SSLPs had only a weak grasp of patterns of service use, for example:

- how many families consumed most of their home-visiting service;
- how many went on to join groups or other activities;
- how far particular users, such as families with disabled children or parents with learning difficulties, were accessing their services.

The most effective SSLPS visited had embedded a rigorous approach to monitoring and review. They expected every activity to identify outcomes and to report on them, as well as seeking regular updates from partner agencies – for example, about their impact on referrals or child health indicators. Although parental involvement in governance and service delivery was an area of strength in many programmes, there were few examples of systematic approaches to gathering parents' feedback on services. Two of the more interesting approaches are described in the box below.

#### Involving parents in planning provision and monitoring outcomes

##### Example 1: Family Action Plans

Family support (through home-visiting) is the main service offered by a SSLP in a predominantly Muslim community, with high levels of special needs and disability in the child population. Family support workers use a simple form to agree an Action Plan with parents and later, to review outcomes. The Sure Start worker sits down on an early visit with the parents to complete a one-page form. This includes:

- a checklist identifying the family's main support needs – reflecting 20 services offered by the SSLP (or by referral), such as play sessions, home safety, behaviour management, parent support, benefits advice, occupational therapy, dietician support or a dental referral;
- a box where they can list other types of support wanted;
- a 'action plan' box asking 'how are we going to meet these needs?', to be filled in by the worker in discussion with the parents. Both sign and date the form.

They revisit the same questions six months later, adding a new page which includes a question about outcomes. Parents are asked to indicate their level of satisfaction on a visual scale ranging from a smiling face to an unhappy one, and a box invites them to comment on outcomes for them. This is repeated at 9 and 12 months, if the SSLP is still involved. A final box notes the date the case was closed, when it was reviewed, and if further support is required.

### Example 2: Electronic monitoring of outcomes

Another SSLP uses survey software to monitor outcomes for each service, tailoring simple questionnaires to capture parents' views. Outcomes for family support are assessed using a checklist based on the 5 *Every Child Matters* outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. These are broken down into about 30 sub-headings, all expressed in plain English - for example, 'being healthy' includes: eating more healthily, taking more exercise, feeling less stressed, ensuring my child sees the dentist regularly. Parents are asked to indicate outcomes against these, on a scale ranging from poor to excellent.

This SSLP has developed a sophisticated approach to monitoring – with the ability to compare parents' perceptions before and after service use, to extract information on the experience of different groups and to demonstrate 'value for money'. This has led them to extend certain services and cut others, and has also helped to build relationships with partner agencies.

### **Value for money**

A few programmes demonstrated good awareness of how far they were achieving value for money and had developed meaningful outcomes measures and performance indicators for their own and commissioned services. They used this information to decide which services to sustain and which to cut [see box]. However, this was an area for development in many more programmes. Factors contributing to improved 'value for money' were:

- **a clear understanding of the programme's role** and how it complemented statutory and voluntary services – for example, expecting services to be '*additional and different*' or filling the gap between universal and specialist services;
- **deploying staff flexibly** to make best use of their skills and strengths - for example, with generic staff providing more 'hands-on' support to families and modelling activities based on the advice of specialist colleagues;
- **robust management of case work** – with regular review of cases that were running on, to consider next steps, whether a referral was necessary and whether the SSLP should withdraw. This was particularly important for family support, where balance between empowerment and dependency needs to be carefully managed. Where statutory services were in deficit or had long waiting lists, this was harder to achieve in practice;
- the use of **groups, drop-ins and courses** to reach a greater number of families and crucially, to 'move families on' – getting them out of the home and providing more sustained opportunities to develop their skills and confidence. A few programmes acknowledged that their purpose-built centres were not as well used as they might be, due to a reliance on home-visiting!

- effective **performance management systems** with regular review of outcomes achieved, as described earlier in this section.

#### **Using evidence to reshape services**

One Sure Start, in an urban area of high unemployment, evaluated its services towards the end of its first year of operation, finding that:

- there was little demand for crèche/sessional childcare – but parents enjoyed coming in for ‘stay and play’ sessions and learning with their children;
- the skilled childcare team felt underused;
- the outreach team felt overwhelmed by constant home-visiting.

This led them to re-shape their services:

- reducing crèche provision, while extending child-parent learning opportunities – in particular, the PEEPs programme, which parents could access via a group or through home visits. All staff were trained in PEEPs as well as some parent volunteers, enabling groups to be extended across the catchment area;
- merging the childcare and outreach team, so that all staff had the opportunity to be involved in centre-based work - running groups and activities - and home visits.

Staff were positive about the merger – which enabled them to broaden their skills, provided more variety and improved their understanding of families’ circumstances. Outreach workers particularly valued the opportunity to interact with families in a fun group environment, diluting the intensity of home-visiting. Linking the two services has enabled the SSLP to offer a wider range of activities, decreased reliance on home-visiting and brought them into contact with many more families.

**Commissioning skills** were an area of concern across many programmes. Many SSLP staff are seconded from partner organisations and the extent to which they are embedded in the programme varies greatly: some SSLP-funded services operate with considerable autonomy. While there were many examples of successful collaborations, some staff appeared to be largely unaccountable in terms of how they spent their time or how they contributed to SSLP outcomes. This was most apparent where:

- they spent all or most of their time with their parent agency, with some reporting that they were under pressure to prioritise agency casework;
- monitoring and reporting arrangements were weak – with partner agencies reporting on contact numbers but providing no meaningful information on the profile or pattern of service use, outcomes or user feedback.

#### **Ensuring a focus on reaching key groups**

Several programme managers acknowledged that the move to Children’s Centres has sharpened their focus on ‘value for money’, as services are extended across a wider area. One of them, in an inner city SSLP with a highly diverse population, meets every contractor (to provide SSLP services) twice a year. She always asks them:

- how they are reaching families of BME origin;
- how they are reaching families with special needs and disabilities.

In future, performance indicators to reflect their work with these groups are to be included in Service Level Agreements.

### 3.8 Funding

The generous funding enjoyed by Sure Start Local Programmes has been valuable in enabling them to improve services for children and families with special needs and disabilities in three key ways:

- **increasing the availability of services** such as family support, sessional childcare (or 'respite') and specialist health provision, which would normally only be offered to those meeting agency eligibility criteria, following an assessment;
- supporting **capital improvements** in early years and community settings – providing accessible, well equipped spaces for parents and children – and funding 'reasonable adjustments' to include disabled children;<sup>50</sup>
- **being able to respond flexibly** to individual needs – funding taxis or childcare to enable families to make appointments, providing one-to-one assistance to support transition to nursery and in most areas, benefiting from good staffing ratios.

The third point is particularly important in terms of how SSLPs have been able to 'add value' to existing network of services. Because they have the capacity to respond quickly and flexibly in crisis situations, SSLPs have been able to 'plug gaps' in statutory services, for example, providing support:

- after sudden illness, injury or deterioration in condition;
- in times of crisis – for example, when a parent has left the family home, become violent, or passed away;
- when there are long delays in statutory processes such as providing disability equipment or preparing a statement of SEN.

To this end, many SSLPs had set aside flexible budgets, managed at the discretion of a senior manager and/or reserved places in their early years provision for children with additional needs.

### 3.9 'Fit' with local services and sustainability

The most effective SSLPs were clear about how they fitted in the network of local statutory and voluntary agencies – and how their role complemented that of statutory and voluntary agencies, for example, taking referrals of families who would benefit from some support, but falling short of agency criteria; following up on families who do not attend appointments and working creatively to engage sections of the community considered 'hard to reach'.

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<sup>50</sup> As required by the Disability Discrimination Act, 1995.

Factors which appeared to have helped them to establish a clear role and coherent fit within the network of local services included:

- a strong Partnership Board and/or confident leadership on the part of the Programme Manager;
- high level commitment of partner agencies – seeing SSLPs as an integral part of their strategic approach to reaching vulnerable families and delivering services on a preventive basis; and at an operational level, working flexibly to facilitate secondments, information-sharing and joint initiatives;
- genuine consultation and on-going review of the SSLP's role within the network of local services, how it could add value and where its role should begin and end;
- regular information-sharing – to underpin service planning and review, with agreement of outcomes measures and broader performance indicators;
- joint training opportunities and shared events to build relationships at an operational level.

Failure to reach a consensus over respective roles could undermine practice. Several programmes reported difficult relationships with community health visitors and GPs, with the result that families who could have benefited from SSLP provision were not referred. Others were unconfident about how well they were reaching their population – including children with special needs and disabilities – as they did not receive regular updates from partner agencies.

Nearly every programme was facing tightened budgets at the time of the research visit, due to moves towards Children's Centres. They varied significantly in how they viewed such developments: some welcomed the opportunity to reach a wider catchment area while others were fearful of losing key posts. Those SSLPs that were most positive about the future were:

- confident about their role within the local network of services (as described above);
- included those SSLPs whose monitoring arrangement enabled them to demonstrate their success in reaching key groups, outcomes achieved and value for money;
- working in partnership with the local authority to influence the roll-out of Children's Centres – in several areas, helping to shape the strategic approach.

By contrast, those that were fearful of major reductions to their services – including several which were working effectively with children with special needs and disabilities – had operated more 'as an island': failing to establish strong working relationships with local agencies and practitioners, and lacking evidence to demonstrate the impact of their services and how far they represented good value for money.

The influence of the programme manager was of critical importance, along with an active Partnership Board – as well as the capacity of local services. Specialist health posts and large family support teams were the most vulnerable to cuts.

### 3.10 Checklist of effective practice for local managers

#### 3.1 Leadership, consultation and governance

- **Strong leadership and clear vision** - from the Programme Manager in particular. It is valuable to have someone with a background in special needs or disability on the senior management team to take a strategic overview of how well children and families with special needs and disabilities are served.
- **Embedding inclusive practice and responsiveness to individual needs** in all aspects of practice – from staff induction through to service review. Making a clear commitment to inclusion in all literature and publicity, to encourage participation.
- **Listening to parents** of children with special needs and disabilities – finding out what they want, the gaps they experience in provision and barriers faced in accessing services. Reviewing this regularly. Giving them a voice on the partnership board or parents forum, along with relevant voluntary organisations.

#### 3.2 Registrations, referrals and reporting

- **Knowing the needs profile of the local population** - drawing on information from partner agencies (health, social services, education and voluntary organisations) to plan and review services.
- Establishing **strong working relationships** with health visitors, midwives and general practitioners to encourage referrals. Linking with the local Child Development Centre, Child Disability Teams and the area SENCO (or equivalent) to ensure they are aware of SSLP/Children's Centre services and to encourage referrals of disabled children and families.

#### 3.3 Joining-up services

- Working with senior managers to exploit the potential of **joined-up working** across services - in terms of reaching vulnerable groups, holistic responses to individual needs, forward planning and support for transitions; particularly in respect of early years services, which had a tendency to operate 'at arms length'.
- Co-locating staff in **multi-disciplinary teams** and **creating cross-cutting roles** – to facilitate information-sharing, problem-solving and

learning opportunities. Encouraging the use of joint visits, shared training and social opportunities, including for commissioned services.

### 3.4 People and skills

- Employing a **special needs/disability expert** in cross-cutting role to undertake some direct work with children and families, advise and support colleagues and influence SSLP/Children's Centre strategy and practice. This role could be shared across a cluster of Children's Centres.
- Ensuring that all frontline staff have the **skills and awareness** they need to work effectively with children and families with special needs and disabilities – including training in disability awareness and safeguarding disabled children.
- Making the most of **in-house expertise** – with specialist staff training others, including local early years providers and helping to review practice. **Flexible staff deployment** – with regular co-working between specialist and generalist staff to help build up skills and provide more sustained input to vulnerable families.

### 3.5 Employment, management and supervision

- **Secondments** where staff spent most of the week at the SSLP and one or two days in their home agency appear to work best – facilitating information-sharing, appropriate referrals and the development of complementary roles. Managers on both sides need to consider coherent, non-duplicative **management** and **supervision** arrangements, as well as professional development opportunities.
- Health, social care and SEN specialists need to have **time protected for preventive work** – raising awareness, contributing to groups and activities and advising and training colleagues. The larger the caseload, the harder it is for staff to undertake preventive work, particularly for those based in their 'parent' agency.
- **Where staff carry caseloads, these need to be actively managed** - with clarity about the aims and expected duration of involvement. This is particularly important for family support work, to strike the right balance between empowerment and dependency.

### 3.6 Information systems

- **Information systems** should provide:
  - a reliable chronology of service use by individual children and families;
  - cumulative case records, with restricted access, to enable planning in more complex cases and service review;



- a system for logging concerns about risks to children’s welfare, with one person who has an overview of all such concerns.
- **Multi-disciplinary forums** help to ensure that practice is safe and effective – allowing staff to discuss and review practice, share learning and problem-solve. Staff with a background in social work and psychology were particularly valued in such discussions, often facilitating them.

### 3.7 Monitoring and value for money

- Collecting **information on service use and outcomes**, able to be analysed by ‘user group’ including special needs or disabilities and ethnicity. Seeking regular updates and outcomes indicators from partner agencies. Comparing costs and outcomes to assess the ‘**value for money**’ of SSLP/Children’s Centre services.
- Regular **feedback from parents** on outcomes for them and their children and regular review of how well services are meeting the needs of children and families with special needs and disabilities in particular.
- Clear monitoring and reporting requirements for **commissioned services** – including an expectation to report on how they are working with children and families with special needs and disabilities and possible barriers to access.

### 3.8 Funding

- **Flexible funding arrangements** to enable rapid responses where crises occur, to support the inclusion of individuals in SSLP/Children’s Centre activities and early years settings, and where possible, to plug gaps in statutory provision.

### 3.9 Fit with local services and sustainability

- **Clear understanding of SSLP/Children’s Centre remit and how it adds value** to local services – for example, with an explicit role around early intervention and reaching out to vulnerable groups. Agreeing processes (or ‘protocols’) for sharing information, making and receiving referrals. Active and on-going communication about services and how they can complement statutory and voluntary provision.
- **Sharing learning** with partner agencies and local providers - disseminating effective practice, such as successful strategies for engaging with minority ethnic groups, consulting parents or promoting children’s language and where appropriate, piloting initiatives such as the Common Assessment Framework and Early Support.

## Part Four: Conclusions and recommendations

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- 4.1 Key conclusions from the research
- 4.2 Towards children's centres: Messages for local and national policy makers

### 4.1 Key conclusions from the research

Although special needs was one of five core service areas which SSLPs were required to deliver by the Government, they were conceived as universal programmes – available to all families in the community. In line with this vision, many SSLPs have not targeted services at children and families with special needs and disabilities, but instead, have worked responsively to meet the diverse needs of local families.

On balance, the way SSLPs have extended and improved local services is the most important way in which they have benefited this group: contributing to higher skills and awareness, increased capacity in key services such as family support and health therapies, and accessible, well equipped buildings. This has provided an improved basis for inclusion and participation by children and families with special needs and disabilities. Nearly all SSLPs felt that they had reduced demand for specialist services, by enabling most children's needs to be met locally.

However, some degree of targeting – for example, employing a special needs or disability outreach worker and offering services such as portage, access to flexible 'respite' childcare and special play sessions – was associated with improved reach of disabled children and their families. A clear commitment to inclusive practice – in policies, literature and publicity – could also help to encourage families to use services that they might otherwise assume were not for them. Those SSLPs that were proactive in reaching out to families with disabled children were in contact with many more – in contrast to those that assumed that there were none living locally.

Families with disabled children face more barriers to services than most. Too often they are left on a separate track – accessing specialist services, but left feeling socially isolated and unsupported. They face multiple pressures and are more likely to be living in poverty. As integrated programmes of support based in local communities, SSLPs – and in future, Children's Centres - are well placed to reach out to such families, to ensure that they are linked into services and community resources. The experience of those that have done so demonstrates that they can make a great difference: helping families to cope and getting children with special needs and disabilities off to a better start in life.

### Which services were most significant?

1. **Family support** emerges as the most significant SSLP service for children and families with special needs and disabilities, playing a critical role in terms of:
  - reaching out to users and overcoming barriers to access – such as concerns about reactions to their child’s behaviour or appearance, language and cultural barriers, learning difficulties, or a suspicion of public services;
  - supporting families to cope through times of crisis – such as a new diagnosis, sudden illness or bereavement – providing emotional and practical support and working flexibly to fill gaps in statutory provision.
2. The expansion in **specialist health services** – notably, speech and language therapy and mental health outreach, offered on a preventive basis – is another key area of improvement. SSLPs have moved beyond the traditional model of service delivery:
  - offering services on a preventive basis, through home visits and group activities;
  - developing the skills and capacity of other services to respond to children’s special needs – embedding effective practice and reducing the need for referrals.

Collaboration with family support workers has improved contact with families who do not keep appointments (traditionally leading to their discharge), including those whose children have challenging behaviour or high support needs, families who face language and cultural barriers and parents with learning difficulties.

3. SSLPs have also done much to improve the availability, quality and accessibility of **early learning, play and childcare** in their communities - providing a better basis for including children with diverse needs. SSLPs have been influential in setting high expectations about the need for services to work flexibly and responsively, and supporting capital improvements, including ‘reasonable adjustments’ for disabled children.

However early years provision was less well embedded than other SSLP services – particularly where it predated them – and some SSLPs had not exploited the potential of linking across services, in terms of: forward planning, supported transitions, raising skills and awareness and providing specialist outreach.

## **4.2 Towards children’s centres: Messages for local and national policy makers**

### **Early intervention**

Early intervention is a key theme within the reform agenda for children's services set out in the *National Service Framework* and *Every Child Matters*. Achieving this shift in practice, in the context of heavy demands on specialist health and social care services, is notoriously difficult. This research points to the value of:

- allocating resources to improve service availability for the under-fives – given that we know that early childhood is a critical period of development, when rapid progress may be made, with enduring benefits;
- offering services on a preventive basis – responding rapidly to emerging special needs, without the need for a formal assessment or the requirement to meet service eligibility criteria (and the associated delay and stress for parents); and more broadly, raising awareness and embedding effective practice in mainstream services, and through groups and activities for new parents.

Recommendation 1: 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 performance management framework for Children's Centres, local authorities and partner agencies.

### **Special needs**

While all SSLPs were working responsively with children and families with diverse needs, some did not perceive a clear role in supporting disabled children or those with more significant and complex needs – assuming that they were catered for by specialist statutory and voluntary organisations or that there were none living locally.

Recommendation 2: National guidance should set clear and consistent expectations about the role of Children's Centres in reaching out to disabled children and their families – 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. [See also recommendation on monitoring, below].

Those SSLPs with a special needs and disability expert, particularly where they exerted a broad strategic influence, were amongst the most effective in working with this group – with inclusive practice embedded in their services and strong links with partner agencies.

Recommendation 3: Children's Centres should employ a staff member with expertise in special needs and disabilities; this 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.

### **Family support**

Family support is the key service that has enabled SSLPs to reach out to isolated and vulnerable families, including those with disabled children, parents with learning difficulties and families facing language and cultural barriers to services. Family support teams were being cut in some areas, as other services were prioritised in the move towards Children's Centres.

Recommendation 4: 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-stretched children's services is not, at present, a realistic alternative, although there were positive examples of collaboration with social services, particularly around supporting parents with learning difficulties.

### **Specialist health services**

Speech and language delay and behavioural, emotional and social difficulties are two of the most prevalent special needs in disadvantaged communities, often linked to children's early experience – yet the availability of speech and language therapy and mental health services for the under-fives (and their parents) is very limited in some areas. These services have a critical contribution to make to Children's Centres impact on children with special needs and disabilities, but posts were being reduced in several areas, due to pressures on NHS budgets.

Recommendation 5: 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.

### **Early years provision**

Early years provision was less well embedded than other SSLP services in several areas – with limited collaboration with health and family support colleagues. While there were some excellent examples of SSLPs working to support the inclusion of children with special needs in local settings and to improve skills and awareness, others had not developed this role. A key challenge for Children's Centres will be to 'add value' to early years provision, linking it into other services to facilitate forward planning and supported transitions for children with special needs and disabilities, developing the skills and confidence of staff in working with this group, and enabling holistic responses to children's needs.

Recommendation 6: 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 raising skills and awareness in local early years settings. Having an area SENCO, pre-school advisory teacher (or similar) based at the SSLP/Children's Centre, or a dedicated special needs outreach worker provides a valuable basis for developing this role.

This should extend to supporting transitions to school and beyond SSLP/Children's Centre services. Few SSLPs had developed this role – which was a cause for concern for local parents and practitioners.

## **Childcare**

The new duties in the Childcare Act 2006 to improve childcare availability for working parents – especially those with disabled children and those on low incomes – are welcome. However, the reality is that many parents caring for disabled children, particularly those who have more than one child, or severely disabled children, find that their caring responsibilities are incompatible with holding down a job. Access to as little as two hours childcare a week was described as a 'lifeline' by parents interviewed in this project, making a critical difference to their ability to cope as a family.

Recommendation 7: Improving the availability of affordable childcare for disabled children and those with challenging behaviour should be a priority in local childcare strategies – including for parents who care for their children full-time. Children's Centres should consider the scope for funding additional childcare sessions for this group, particularly through crisis periods.

## **Performance measurement**

Moves towards monitoring the take-up of services by families with disabled children are welcome. Other groups with special needs who face important barriers to access include parents whose children have challenging behaviour, parents with learning difficulties and minority ethnic families - disabled children of BME origin are at risk of 'double discrimination'.

The lack of accepted definitions for special needs and disabilities in this sector continues to undermine attempts at data collection and service review, both locally and nationally – national data on children with special needs and disabilities using SSLP services were considered too unreliable to use in this report. Given difficulties in defining special needs for young children, consideration should be given to developing activity-based approaches – such as benchmarking the number of families accessing portage services or mental health outreach to build up a fuller picture.

Recommendation 8: Consideration should be given as to how to monitor the take-up of Children's Centre services by these groups. This will require a more consistent use of definitions of special needs and disabilities, for this age group.

## **Closing thoughts - the big picture**

This report is written at a time of great change – in terms of structural reform to create unified Children’s Services and integrated local delivery through Children’s Centres.

SSLPs benefited from being well resourced and having the flexibility to respond creatively to the needs of the local community. Although the first waves of Sure Start Local Programmes pre-dated the *National Service Framework* and *Every Child Matters*, in many ways they encapsulated the approach which these seminal policy documents envisaged: early intervention, child and family centred services, joined-up working and reaching out to vulnerable sections of the community. This research suggests that SSLPs should have much to contribute to the change agenda for children’s services:

- sharing learning about how to deliver integrated and preventive services;
- reaching out to vulnerable groups, including families with disabled children, parents with learning difficulties and minority ethnic communities;
- modelling child and family-centred approaches to meeting the needs disabled children and their families, in line with *Early Support* principles;
- supporting the delivery of Children’s Centres, particularly in terms of the wider offer of health and family support services; and
- meeting the aspirations of the Childcare Act 2006.

The challenge now is to learn from their experience – building on what has worked and engaging SSLPs in developing local strategy and in supporting the roll-out of Children’s Centres.

## Annex A: Research methodology

1. Overview of research methodology
2. Project hypotheses
3. Request to fieldwork sites
4. Request to parents

### 1. Overview of research methodology

#### Research design: December 2005 - January 2006

- Review of key literature and policy framework.
- Exploratory discussions with stakeholders in the voluntary sector and academia - including London and York Universities, the Council for Disabled Children, Mencap, Contact-A-Family (national and local family support workers), the Children's Society, Barnados, the Maternity Alliance, Early Support (and ES Evaluation researchers) and KIDS.
- Review of NESS evidence:
  - Local evaluations – search of NESS website for evaluations including the words 'special needs', 'special educational needs', 'disability' or 'disabled', and review of all such documents.
  - National survey – analysis of answers to question 14 (telephone survey version) covering 'Support to families and children: specific services'. SSLPs were asked to indicate 'Special provision ... for children with special needs or disabilities and their families' from a list of 20 options, including portage, respite sessions, clinical psychologists, special support workers etc.
  - Programme variability study – analysis of evidence for SSLPs rated highly on indicators 7, 8 and 11: 'multi-agency teamwork', 'clear pathways for users to follow in accessing specialist services' and 'strategies for identifying users'. Also, analysis of SSLP ratings on all indicators (a proxy for overall effectiveness) and against a wider basket of relevant indicators – those mentioned above, plus indicators 4, 16, 17 and 19: 'empowering users', 'showing innovative features', 'accommodating the needs and preferences of a wide range of users', and 'having a welcoming and inclusive ethos'.
  - Cost effectiveness module – analysis of reported spending on special needs for each year from 2000/01 to 2003/04.
  - Review of themed studies already published - including the Implementation Module Integrated Report (2004), Improving the Employability of Parents (2004), Early Learning, Play and Childcare



Services (2005), Buildings (2005) and Maternity Services (2006 – read in draft).

- Visits to 3 SSLPs, meeting a variety of practitioners and parents.
- Project hypotheses drawn up [included in this annex].
- Development of research tools and evidence-recording matrix, based on the hypotheses.

### Selection of fieldwork sites

NESS themed studies are descriptive, not evaluative: they are intended to describe aspects of SSLP services and draw lessons from their implementation, not to judge how well SSLPs are working overall or their impact. The purpose of this study was to explore how SSLPs were meeting the needs of children and families with special needs and disabilities, to inform improvements in local practice and future policy on Children's Centres. Consequently, the main criterion for selecting fieldwork SSLPs was evidence of effective or innovative practice in working with this group.

A 'long list' of potential fieldwork sites was compiled, drawing primarily on NESS evidence (as described in some detail above), including:

- high rating in programme variability study;
- high rating in national survey (Q14: special provision)
- high spending on SEN, year-on-year (cost effectiveness module)
- relevant local evaluations published on the NESS website
- information published on the SSU website about SSLP services, in particular, those targeted at children and families with special needs and disabilities.

This produced a list of 50 potential fieldwork SSLPs. From these, 12 were selected to produce a sample that was representative in terms of socio-economic and BME profile (based on NESS Local Context Analysis data<sup>51</sup>) and including a spread in terms of:

- lead partner – health, local authority, voluntary sector or 'other'
- region
- type of area – most SSLPs are urban, but the sample included some inner city, some suburban, some out-of-town housing estates and one rural.

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<sup>51</sup> The Local Context Analysis (another strand of NESS) identified 5 'types' of SSLP community, based on socio-demographic and economic characteristics, typified by relative deprivation and the proportion of ethnic minority families. Our sample of fieldwork sites was representative of these 5 types.

## Fieldwork

Fieldwork was carried out in 2 phases – February-April and June-July 2006, with a month in between to write up emerging findings for discussion at the mid-project Advisory Group, and to set up the second round of fieldwork.

A document review was carried out before each visit, along with a web search. SSLPs were asked to provide:

- main information booklet / leaflet for parents (describing services etc.)
- most recent annual report and/or delivery plan
- special needs policy and/or equal opportunities policy
- relevant service evaluations.

Each visit involved two days on site, interviewing staff and parents. In several areas, partner providers were also visited – for example, local playgroups or the CDC (where the SSLP worked closely with them). In each area, semi-structured interviews were held with:

- programme manager
- special needs lead, if there was one
- service manager or special needs lead for each of health, family support, early learning and childcare
- key health specialists – typically a speech and language therapist, mental health outreach worker and health visitor
- monitoring officer
- any others whom the SSLP felt were relevant to the study
- parents - individually or through a small group discussion.

Almost 150 staff were interviewed during fieldwork (average of 12 per site) and 33 parents (average of 3 per site) – see table below.

<b>Fieldwork interviews carried out</b>	<b>No. interviewed</b>
Programme manager (PM)	11
Deputy PM	2
Change manager	2
Family support/outreach manager	7
Special needs/inclusion outreach worker	6
Other family support workers	8
Portage workers	5
Children's centre manager/early years coordinator	6
Childcare development officer	5
Senco	5
Pre-school advisory teacher or area senco	5
Learning mentor	1
Other crèche, playgroup and nursery staff	10
Local nursery, playgroup and primary heads	12
Local family centre manager	1

<b>Fieldwork interviews carried out</b>	<b>No. interviewed</b>
Social worker	1
Health manager	3
Clinical psychologist	4
Psychotherapist / counsellor	3
Primary mental health worker / cty. psychiatric nurse	3
Speech and language therapist / assistant	9
Physiotherapist / assistant	1
Community paediatrician	1
Health visitor	12
Midwife / assistant	6
Data clerk / analyst	9
Local authority (LA) strategic lead	3
Multi-agency support team outreach worker (LA)	1
Early Support coordinator (LA)	2
Voluntary organisation lead	4
Board Chair	1
<b>TOTAL – practitioners</b> (average per visit = 12)	<b>149</b>
<b>TOTAL – parents</b> (average per visit = 3)	<b>33</b>
<i>Note: Each interviewee counted once only on the basis of their main role.</i>	

Interview notes were typed up against the project hypotheses. Interviews with parents were recorded (with their consent), typed up verbatim and analysed thematically. The researcher also recorded her impressions against a set of key research questions.

Fieldwork sites were also asked to complete short questionnaires intended to provide a snapshot of:

- the number and perceived profile of children with special needs and disabilities
- relevant training undertaken by SSLP and early years staff
- the range of specialist services provided
- the range of family support offered.

Finally, they were asked to provide contact details of colleagues in key partner agencies – NHS, local authority and voluntary sector – with whom telephone interviews were carried out, towards the end of phase two. This enabled the researcher to test out key conclusions (for individual SSLPs) as well as exploring a set of standard questions with each. Profile of these interviewees:

<b>Agency / organisation</b>	<b>No. interviewed</b>
Local authority – education	14
Local authority – social services	9
Health	8
Voluntary sector	5
Board members (NB overlap with other)	13

categories)	
<b>Total</b>	<b>41</b> (average per site = 3)

## 2. Project hypotheses

The main purpose of the hypotheses was to provide a framework for the research. Research tools – interview schedules, questionnaires and recording instruments – were derived from them; fieldwork findings were recorded against them; and judgements about the effectiveness of individual SSLPs are based on how their practice measured up against this framework.

### Key themes

- A. User identification
- B. Supporting families
- C. Positive ethos and 'can-do' attitudes
- D. Staff skills and confidence
- E. Inclusive, accessible and affordable services
- F. Access to specialist services
- G. Promoting outcomes and supporting transitions
- H. Strategy and planning
- I. Effective use of resources

#### **A: User identification**

1. The SSLP knows of all families with children with disabilities/special needs in their area and actively encourages them to take-up services.

- approx. how many working with, common needs, how many severe and complex?
- how does the SSLP know of children with disabilities / special needs?
- how does it seek to engage with them?
- is support offered ante-natally or around 'news-breaking'?
- who reaching better than before, who perhaps missing?

#### **B: Supporting families**

2. The SSLP offers advice, support and information to parents of children with disabilities or special needs and encourages them to get involved:

- parent support: enhanced home-visiting, key workers, advocacy, support with statementing, special parents group
- home-learning: portage, speech and language development, sleep, behavioural and other programmes [also covered in G: outcomes]
- care/respite: sessional respite care, daycare/crèche, help with accessing suitable childcare
- information and advice: info. on conditions/impairments, advice on benefits and direct payments, housing issues, service directories, sign-posting to voluntary organisations. Provided in minority languages and diverse formats, as appropriate.
- empowerment, encouragement to take up services and get involved

### **C: Positive ethos and ‘can-do’ attitudes**

3. The SSLP has a positive ethos towards children with disabilities and/or special needs and a *can-do* approach to meeting their needs.

- is the literature explicit about welcoming these children and their families? Are positive images displayed?
- is this considered a core value by staff and parents?
- examples of going the extra mile to make things work
- balance: mainstream-special provision within SSLP?

### **D: Staff skills and confidence**

4. Staff have the skills and confidence to recognise if a child may have special needs or a disability and know how to respond.

- which staff play an active role in ‘needs identification’ and specialist advice/support to colleagues [and model used]?
- what training is provided in terms of special needs/ disability awareness and specialist knowledge or skills?
- who provides the training? is it undertaken jointly – with whom?
- is training provided to volunteers, parents and others?

### **E: Inclusive, accessible and affordable services**

5. Children with special needs and disabilities are able to participate fully in early learning, care and play provided by the SSLP.

- is early learning/care/play provision made by the SSLP fully inclusive?
- what special EL/play/care sessions are available (separate or integrated?)
- does the SSLP provide equipment to enable participation?
- have staff been trained in alternative communications, such as Makaton?
- examples of how have supported participation
- how has SSLP added value to EY provision?
- views on quality of provision?

6. SSLP premises are accessible and children with special needs.

- how many of the buildings used are accessible to wheelchair users?
- DDA awareness: examples of making ‘reasonable adjustments’; does the SSLP have an accessibility plan and what are the priorities?<sup>52</sup>
- does the SSLP have a risk management policy covering lifting and handling, invasive/intimate care and physical restraint?
- are there any disabled children / parents who have not been able to attend – which aspects of provision and why?

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<sup>52</sup> Note: only EY providers constituted as schools are *required* to have an accessibility plan.

7. Services (esp. childcare) are affordable to families with disabled children.

- do families of disabled children face additional charges for SSLP services e.g. childcare? (and same full entitlement as others?)
- does the SSLP subsidise additional costs (e.g. respite, crèche, transport)?

8. The SSLP supports and promotes the development of inclusive practice beyond its immediate catchment area.

- is special needs/disability outreach or training offered to local providers?
- are specialist facilities (e.g. multi-sensory room or toy library) open to them?
- are disabled children living outside the catchment area able to benefit from SSLP facilities and outings?

#### **F: Access to specialist services**

9. The SSLP has strong links with health, education (SEN) and social care, ensuring swift access to specialist assessment, advice and provision.

- does the SSLP have an agreed process for making referrals to health, education and social services? how well does it work?
- what has been the impact on referrals?
- does the SSLP take on an advocacy role?
- does it play a role in statementing?
- has it developed fast-track procedures for multi-disciplinary assessments?
- does it also receive referrals from other agencies – what for?
- can SSLP specialist services be accessed by those living outside the area?

10. Which specialist services<sup>53</sup> are available on-site and which require referral?

11. How do SSLP services 'fit' within the network of provision locally?

- strategic fit with local services and basis on which staff are employed
- knock-on effect on local services?
- what has it added to the availability of services for disabled children and their families? what *enabled* it to do this?
- what are the key improvements families with disabled children have seen?
- will this change under Children's Centre developments?
- has it overlapped with ESP or other area initiatives – implications?

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<sup>53</sup> Services normally provided by health, social services or the local education authority, following an assessment of need.

## **G: Promoting progress and supporting transitions**

12. The SSLP provides special programmes to promote the development of children with special needs and/or disabilities.

- examples – portage, PEEPs, early bird etc – and how are they delivered?

13. The SSLP monitors the progress made by individual children with their families, setting goals for early learning, health, socio-emotional development.

- how are case records kept – separately or jointly? any system for regularly looking at child/family' progress across services?
- how is progress monitored?
- how are parents involved in this process, are their views sought?
- are views of children sought?

14. The SSLP has strong links with local schools and EY providers and systems in place to support effective practice and smooth transitions.

## **H: Strategy and planning**

15. The SSLP consults parents of children with special needs/disabilities in shaping and improving its services and regularly reviews provision for this group.

- is there a disability/SEN rep. on the Board (parent or other?)
- has the SSLP consulted disabled parents/parents of disabled children specifically and did this lead to any changes?
- has it ever carried out a special needs/disability review - which tool was used?

16. The SSLP is aware of changing patterns of needs locally and this is reflected in strategy and planning.

- how are they aware of this – what information sources?
- what are their perceptions of changes in the needs profile locally?

## **I: Effective use of resources**

17. The SSLP is aware of the need to achieve value for money in the services it provides.

18. The SSLP has been able to use additional funding to support participation by children with special needs/disabilities and their families through:

- creative use of modest funds (examples)
- core staff training
- employing support assistants



- buying-in specialist staff time
- subsidising childcare/crèche, transport or other costs
- providing disability equipment
- major capital developments – e.g. building adaptations
- offering specialist provision, not available otherwise.

### **3. Request to fieldwork SSLPs**

#### **Fieldwork visits: Special Needs Study, National Evaluation of Sure Start**

##### **Background**

A number of 'themed studies' are being done within the National Evaluation of Sure Start (NESS), to allow key issues to be explored in depth. This project is investigating:

1. how Sure Start Local Programmes (SSLPs) are meeting the needs of children and families with special needs and disabilities - both in terms of universal and specialist provision;
2. how SSLPs have improved services for this group and which factors have been significant in enabling or impeding progress;
3. how practice varies from programme to programme and for different 'users';
4. longer-term sustainability, in the context of Children's Centre developments.

Our main aim is to learn from effective local practice and so, to support wider improvements for this group. We will gather case studies and models of good practice and draw out lessons to inform the development of Children's Centres.

##### **Research approach**

Much background research has been done, including analysis of NESS and DfES evidence, internet searches and consultation with groups representing children and families with disabilities.

The main element of new research involves a dozen fieldwork visits to SSLPs which appear to have done much to develop services for children and families with special needs and disabilities. We would very much like to visit your programme.

##### **Scope of fieldwork**

Visits will take place over 2 days. The exact scope will vary, depending on the local configuration of services, but ideally it should involve:

- introductory interviews (up to 90 minutes) with the programme manager and special needs/disability key contact (if there is one);
- an interview (up to 1 hour) with the head of home-visiting/outreach/family support, or special needs specialist within this team (if there is one) ;
- an interview (up to 1 hour) with the early learning/play/care manager and visits to one or two local settings that you work with;

- short interviews (45 minutes) with several ‘specialist’ staff working with children and families with special needs and disabilities – for example, speech & language therapists, psychologists, mental health workers, social workers, health visitors and midwives. Interviews may be combined, as appropriate.
- a short discussion (up to 30 mins.) with your data-recording officer, to find out about how you compile your special needs data returns and monitor contacts;
- meetings with any other colleagues who are particularly interested or involved in this area, at your recommendation.

**Parents’ views** form an important element of the research. We would like to meet several parents or carers whose children have special needs or disabilities, ideally for an informal group discussion (up to one hour). Otherwise we could meet individual parents, at your recommendation.

To put the research in context, we will also carry out **short phone interviews** with key colleagues in local health services, social services, education and voluntary groups, after the visit; and with the Chair or special needs rep. (if there is one) on the Programme Board. We will ask you to suggest who we should speak to.

### **Next steps**

I hope that you will be happy to take part in the research! I have currently blocked out ... [add dates]. It would be very helpful if we could agree dates as soon as possible, as I will be travelling all around the country during this period. Your help would be greatly appreciated in scheduling the visit - please could you let me know if there is administrator who could assist with this.

To prepare for the visit, I would be grateful if you could now send me your:

- main information booklet / leaflet for parents (describing services etc)
- most recent annual report and/or delivery plan
- special needs policy, if there is one
- relevant service evaluations.

### **Ethical guidelines & confidentiality**

Research will be conducted in accordance with NESS ethical guidelines. NESS studies do not identify local programmes or individuals – all case studies are anonymised and care is taken not to allow individuals to be identified. Permission would be sought if the researcher subsequently wishes to identify good practice in other published material (e.g. in an article), but less effective practice will not be identified at any point. Parents’ written consent will be sought before embarking on any discussions with them.

### **Contact details**

Anne Pinney, independent researcher

*Special needs themed study - National Evaluation of Sure Start*

Email: / Mo: / Tel:	Postal address
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Please don't hesitate to get in touch if you have any questions. And last but not least, thank you very much!

#### 4. Request to parents

# NESS

NATIONAL EVALUATION OF SURE START



### National Evaluation of Sure Start : Special Needs Study

Dear parent,

We are doing some research in your area to find out how Sure Start is meeting the needs of children and families with special needs or disabilities. We want to hear about what is working well – and what’s not working so well - to help improve services all around the country, in future.

As well as talking to staff, it is important for us to hear what local parents think. **Would you be happy to talk to one of our researchers?**

It is completely up to you if you want to do this. It would involve an informal chat, taking up to 45 minutes, at your local Sure Start centre, possibly along with several other parents. You can stop the interview at any point, if you want.

The researcher will need to take notes and record the interview, to help her remember what you say. Her records will not be shared with anyone else. Neither you nor the programme will be identified when she writes up the research - it will be made anonymous, so that what you say cannot be linked back to you.

If you are happy to take part in the research on this basis, please sign here:

SIGNATURE	PLEASE ALSO PRINT YOUR NAME
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If you have any questions about this work, please call the project manager, Anne Pinney, on xxx or ask one of the staff to get in touch with her for you.

***Thank you very much!***

## **Annex B: Select bibliography**

Audit Commission, 2002, *Special educational needs: A mainstream issue*

Audit Commission, 2003, *Services for Disabled Children: A review of services for disabled children and their families*

Audit Commission, 2003, *Let me be me: A handbook for managers and staff working with disabled children and their families*

Beresford, B., 2003, *Community equipment: use and needs of disabled children and their families*, University of York

Campell, L., Cowdell, G., Parrot, M., March 2005, *The National Centre for Early Intervention Feasibility Study (Final Report)*, National Children's Bureau

Department for Education and Skills, 2002, *Supporting families who have children with special needs and disabilities*

Department for Education and Skills/Department of Health, 2003, *Together From the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*

Department for Education and Skills, December 2004, *Choice for parents, the best start for children: a ten years strategy for childcare*

Department of Education and Skills (Sure Start Unit), November 2005, *Sure Start Children's Centres: Practice Guidance*

Department for Education and Skills, 2004, *Removing Barriers to Achievement: The Government's Strategy for SEN*

Department of Health, 2004, *National Service Framework for Children, Young People and Maternity Services – Standard 8: Disabled Children and Young People and those with Complex Health Needs*. Also, research summary behind this.

Department of Health, 2003, *What to do if you're worried a child is being abused*

HM Government, Sept 2003, *Every Child Matters*

HM Treasury, DfES, 2007, *Policy review of Children and Young People: a discussion paper*

Lord Laming, *The Victoria Climbié Inquiry – Report of an Inquiry by Lord Laming*, HMSO, January 2003

Melhuish, E. C., *A literature review of the impact of early years provision on young children, with emphasis given to children from disadvantaged backgrounds*, National Audit Office

Ofsted, 2005, *Removing barriers: a 'can-do' attitude: A report on developing good practice for children with special needs in early years childcare and education in the private and voluntary sectors*

Prime Minister's Strategy Unit, 2005, *Improving the Life Chances of Disabled People*

Schweinhart, Barnes & Weikart, *Perry High/Scope Preschool Project*, 1993

Simon, J., 2006, *Diversity matters: Good practice in services for disabled children and their families from black and other minority ethnic communities*, Council for Disabled Children

Sylva et al, *Early Years Transitions and Special Educational Needs project*, on-going

## **Annex C: Acronyms used in this report**

BME	Black and minority ethnic
CAF	Common Assessment Framework
CDC	Child development centre (NHS)
CDT	Child disability team (social services)
DDA	Disability Discrimination Act
DfES	Department for Education and Skills
DH	Department of Health
ECM	<i>Every Child Matters</i> (see bibliography for full reference)
EY	Early years (i.e. services for under-fives)
HMG	Her Majesty's Government
LA	Local authority
NESS	National Evaluation of Sure Start
NHS	National Health Service
NSF	National Service Framework for Children, Young People and Maternity Services (see bibliography for full reference)
NVQ	National Vocational Qualification

PCT	Primary Care Trust
PEEP(s)	The Peers Early Education Project
PMSU	Prime Minister's Strategy Unit
SEN	Special educational needs
Senco	SEN coordinator (in schools or early years settings)
SSLP	Sure Start Local Programme



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