department for
education and skills
creating opportunity, releasing potential, achieving excellence

National Audit of Support, Services and Provision for Children with Low Incidence Needs

Peter Gray

The Special Needs Consultancy

Research Team:
Pat Bullen, Lynne Duckett, Sue Leyden
Ian Pollard and Rob Skelton

With support from:
Gervase Leyden and Katie Fraser

National Audit of Support, Services and Provision for Children with Low Incidence Needs

Peter Gray

The Special Needs Consultancy

Research Team:

Pat Bullen, Lynne Duckett, Sue Leyden
Ian Pollard and Rob Skelton

With support from:

Gervase Leyden and Katie Fraser

CONTENTS: Page

NATIONAL AUDIT OF SUPPORT, SERVICES AND PROVISION FOR LOW INCIDENCE NEEDS

EXECUTIVE SUMMARY:

Introduction:

1.   This Audit was commissioned by the DfES as part of its strategy for SEN and Inclusion ('Removing Barriers to Achievement). It was carried out by The Special Needs Consultancy.

2.   The Audit arose from concerns about the availability and consistency of support provided, across the country, for children with low incidence needs, and the need for some to be placed at a considerable distance from home in order to access the provision they require.

3.   The purpose of the Audit was to:

   (i)   Gain a picture of how Local Authorities meet the needs of children with low incidence SEN and potential local/regional/national examples of good practice/expertise

   (ii)   Explore gaps in services, support and provision, and how these gaps can be/are being addressed

   (iii)   Use the above to support and inform policy and practice development for regional and local planning and provision, so that more children have their needs met locally, as well as informing the development of 'Regional Centres of Expertise'

4.   The term 'low incidence' is used to describe needs that occur less frequently and may require a more specialised response. The categories included in the project specification were as follows:

   1. severe multi-sensory impairments
   2. severe visual impairment
   3. severe/profound hearing impairment
   4. profound and multiple learning difficulties
   5. severe autistic spectrum disorders
   6. severe behavioural, emotional and social difficulties

To ensure that the Audit was viable, these groups were linked together as follows, with a focus on the more complex end of the continuum:

(i)   severe sensory/multisensory impairments (visual/hearing/deaf-blind)
(ii)   severe autistic spectrum disorders (ASD)
(iii)   severe behavioural, emotional and social difficulties (BESD)

Issues relating to other low incidence groups were also raised during the course of the Audit and were included in the findings (physical/health care needs; profound and multiple learning disabilities).

5.   In line with the holistic emphasis of Every Child Matters, the Audit looked at a broad range of needs and services/provision (education, social care, health, social/leisure).

6.   The Audit involved an initial scoping phase (interviews with national stakeholders, including representatives from key voluntary organisations and the independent/non-maintained sector; and a literature/resource review). This was followed by a questionnaire, which was sent to all Local Authority areas in England. Questionnaires were completed by the 3 main statutory agencies (Education, Health and Social Services). Finally, focus groups were held in each Government Region[1], involving a wide range of local stakeholders (statutory agencies and voluntary sector organisations, schools, parent partnership representatives, and independent/non-maintained providers).

7.   The response and participation rate was very good with questionnaire returns received from 90% of Authority areas and nearly 400 people overall attending the focus groups.

Overview of findings

1.   The Audit has shown a significant level of agreement about key issues and development needs. A similar picture has emerged across all sources of evidence (scoping interviews, literature review, questionnaire responses and focus group discussions), lending further support to the validity of the findings.

2.   While there are some differences between the three main groups (Sensory/ASD/ BESD), in the issues they present, there is also a high degree of commonality, particularly at the severe end of the continuum, where needs are more complex and multiple. There are also similarities in relation to other types of low incidence needs (such as physical/health care and profound/multiple learning disabilities).

---

[1] And London Subregion

3.   ASD and BESD issues are regarded as more challenging, compared to the area of sensory/multisensory impairments. However, in the latter, there are concerns about recruiting and retaining practitioners with relevant expertise.

How Local Authorities meet the needs of children with low incidence SEN

4.   Local authorities generally seek to maintain a continuum of provision for children with low incidence needs. For those with more severe/complex needs, most Authorities make some use of provision outside their area. However, the level of use of out of Authority placements varies significantly across the country.

5.   Authorities generally have some level of specialist services and provision to meet low incidence needs, in terms of education support teams and mainstream unit/ special school provision. However the shape and form and the extent of these varies.

6.   Even where there is dedicated educational provision for particular types of low incidence needs, this does not always cover the full range of individual pupil difficulties. Difficulties are experienced in providing effectively for children with more complex and multiple difficulties, who can have needs across a number of different dimensions.

7.   Social care/family support services are generally less differentiated, although there is some evidence of increasing specialisation in some areas of the country.

8.   Health Authorities provide a range of therapy services for children with low incidence needs, but the capacity of these varies. There continue to be significant recruitment issues in some areas. Therapy services are looking to develop more cost-effective ways of service delivery that will enable their support to be better targeted.

9.   Children with low incidence needs should have access to a range of other types of service (eg Youth Service, Connexions, CAMHS). However, there is evidence of some barriers in these areas of provision.

10.   In most Authorities, there appear to have been improvements in the delivery of services and support in the early years, and these are being reinforced by the Government's Early Years Support Pilot Programme. At the other end of the age scale, there are a number of specialist colleges that focus on particular kinds of low incidence needs. The voluntary sector and the LSC are keen to promote better access and opportunities for such students in their local area, through improvements in the mainstream FE sector.

11.   Authorities assess the quality and appropriateness of their services, support and provision in two ways: at the individual pupil level, through statutory reviews and support service monitoring. Different agencies and areas also make use of

consumer feedback from parents, schools (and sometimes from young people, directly). At a broader level, agencies and services are developing different ways of self-evaluation, and schools are increasingly required to evaluate outcomes and seek parental views.

12. A number of Authorities are starting to review their services and provision more holistically, involving a broader range of stakeholders in identifying issues and ways forward. The Pan Dorset review cited as a vignette in this report is a good example of a systematic approach that has led to more coherent and collaborative planning for the development of a range of local services.

13. In the area of sensory impairment, Authorities are starting to make use of the national standards published by the DfES (2002) and more detailed assessment approaches are currently being developed in the South East region.

14. There is evidence that clearer national guidelines for good practice would be welcomed as a basis against which local quality can be judged more systematically. These will need to go beyond process and start to define desired outcomes across the range of Every Child Matters dimensions.

Gaps in services, support and provision and how these are being/could be addressed

15. The key gaps in service, support and provision for these three groups are not in relation to specific skills and interventions, but to the broader areas such as family support/respite care, support for mental health issues, and better social/leisure opportunities, where greater skills and capacity are needed. Priority needs to be given to developments in support and provision for older children as they move towards adulthood.

16. The task is not to improve individual elements of provision *in isolation*, but to develop more coherent packages of support that address all aspects of children's lives. For children with severe low incidence needs, joined-up responses are the key to making local provision more inclusive and effective.

17. There are encouraging examples of good practice at local, regional/subregional and national level that could be built on and extended.

18. Provision for more complex difficulties has to be supported by improvements in universal provision for the broader continuum of special educational needs.

19. There is also a need for significant development in the mainstream secondary school sector. Difficulties experienced in this context are leading to placement breakdown for some pupils with low incidence needs who, with better support, should be able to access the broader curriculum.

20. Planning for 14+ progression needs to be better informed and more person-centred, and involve all relevant services. In some areas, more specialised knowledge and specific skills are needed within generic services (such as Connexions).

21. There is a priority need for development in local FE college provision. More strategic planning of college provision (and proper funding of support) will be needed to ensure that students with low incidence needs are better catered for.

22. There are new opportunities within the further education sector for improving local provision, in the light of strategic changes within the Learning & Skills Council and the recent publication of the Little Report. This should create greater capacity for local/regional developments. However, there are some continuing barriers to progress in that sector, such as funding for transport.

23. Child and Adolescent Mental Health Services (CAMHS) need to be more accessible to young people with low incidence needs. There is evidence that disability access should be improved (for children with sensory impairments and/or complex learning disabilities). There is also a call for changing patterns of support for mental health issues, with specialist workers linked more closely to frontline professional staff.

24. Gaps in family support and short break/respite provision come out very strongly from this Audit. These are a major factor in parents/carers opting for placements away from home. There are also limits in the availability of suitable extended day/social and leisure opportunities, which puts further pressure on families and restricts the range of some young people's experiences.

25. Local authorities find it more difficult to meet needs when young people have multiple impairments or issues that cut across a range of service/provision boundaries. This argues for more flexible service responses that are more child-centred and responsive to individual needs. Local Authorities also appear to have more difficulties when their special provision is based on traditional categories. More generic 'complex needs' provision tends to mean that fewer children 'fall through the net'.

26. Generally, Local Authorities find it more difficult to meet needs locally where there are significant behavioural issues, and where provision is breaking down on a number of fronts (school/home/community). However, there are also a number of children placed out of their own area where there are differing views between parents/carers and statutory services about the ability of local provision to meet their child's particular needs.

27. In relation to services/provision for young people with severe/profound sensory/multisensory impairment, Local Authorities are trying to address the gaps through:

- *Better liaison with local LSCs and other partners, and broader regional/subregional planning of FE options*
- *Multi-agency transition teams and transition protocols*
- *Improving access to extended care/leisure opportunities*
- *Closer links between specialist workers and CAMHS*
- *Joint commissioning of specialist services and provision*

28. For those with <u>severe/complex autistic spectrum disorders</u>, the priorities have been to develop:

- *More flexible provision within local services and schools (special and mainstream) in order to cater better for more significant individual needs*
- *Increased opportunities for extended care and leisure activities, with staff more skilled/better trained in responding to ASD needs*
- *More personalised planning for young people at the 14-19 stage*
- *Multi-agency training and increased partnership with parents and the voluntary sector*

29. For those with severe/complex behavioural, emotional and social difficulties, Local Authorities are seeking to address the gaps through:

- *More flexible/accessible services (eg intensive multiagency support teams) linked to young people whose education/care placements are most vulnerable*
- *Multi-agency decision-making panels, able to target a range of resources at critical points in some children's lives*
- *Development of mental health worker and keyworker roles*

Implications for regional/local planning and development (and RCEs)

30. There is evidence from this Audit of a considerable amount of expertise available across a wide range of providers (LEA-maintained schools, support services, statutory agencies, voluntary organisations and the independent/non-maintained sector, not forgetting the experience, skills and perspectives developed by parents/carers and young people themselves).

31. There are a wide number of ways in which this expertise could be better directed. However, the overriding emphasis emerging from this Audit is that it should be used to enhance and support local capacity, to skill and not to deskill, and that it should be part of a broader culture of continuing development across all relevant services.

32. Extension of expertise would be supported by more effective processes of local, subregional and regional planning (for example, through more systematic

mapping of development needs and skill shortages, identifying local/regional resources and improving coordination of developments, so that these can draw on the strengths of a broader range of providers).

33.   Generally, the Audit points to the need to strengthen generic provision and services, using specialist expertise in a developmental way. There is not a strong push for the creation of more and more specialist facilities. However, there is a need to ensure that specialist skills continue to be available and that sufficient specialist staff can be recruited and trained.

34.   There is little overall support for the development of regional centres of expertise in terms of specialist 'provision for children', except in a very limited capacity. However there is general support for improved regional and subregional planning and review to ensure more consistent levels of good practice, and more coordinated opportunities for networking and training.

35.   The Audit challenges the view that expertise has intrinsic value. Its usefulness needs to be measured in terms of its contribution to building local capacity, so that *all* children with low incidence needs can benefit. This implies that expertise is best delivered through effective training and networking opportunities, rather than being 'held' in a centre at a distance from day-to-day practice. There is clearly an important place for research and development, but this needs to be connected with and informed by practice issues. There is also a continuing place for direct service provision of a specialist kind, but there should always be a clear emphasis on extension and generalisation of good practice to a wider range of providers.

36.   Nationally, there needs to be a coordinated programme of research and development linked to key areas of low incidence needs, with proper dissemination and close links with the range of stakeholders. Good practice examples need to be made available, particularly those that include children with more complex needs and that make effective use of expertise to enhance local provision.

37.   Regionally, the range of relevant expertise available needs to be mapped and better coordinated to provide more consistent training opportunities for all agencies. Regions should continue to support networks and interest groups, drawing together staff from statutory agencies, voluntary organisations, parents and the independent/non-maintained provider sector.

38.   Locally, expertise could be supported and extended in a similar way. The Audit indicates that there have been significant benefits where different services have come together for multi-agency training, so that there are better common understandings and a common language/repertoire of approaches available.

39.   A number of ways forward are recommended in this report. The Audit indicates that developments in each local area should be based on a coherent and coordinated assessment of current services and provision, against clearer national standards. Regional developments need to support the building of local capacity, so that good quality provision is available more consistently locally for all children with low incidence needs (and particularly those most at risk).

The feasibility of auditing specialist services, support and provision on a regular basis

40.   The National Audit has been productive and a wide number of stakeholders have been engaged. However, obtaining a comprehensive picture has been labour-intensive. Moreover, the wide scope of its remit has meant that the focus has inevitably been on broader and more general issues. While it may be important to revisit these at a future date (in 5 years time) to assess the degree of progress in meeting current gaps, a more immediate priority is to support the process of more locally-based reviews.

41.   These should draw more heavily on consumer experience (parents/carers and young people themselves) and identify more specific points for development at local/subregional/regional level. The process of the Pan Dorset review (described in section 4.84 of the report) points to a possible way forward.

Recommendations:

1.   The DfES should give a clear steer to regions and Local Authorities with regard to good practice for children with low incidence needs, through publication of this report and active dissemination of its findings. The report should be discussed by relevant regional stakeholders and an action plan developed at this level. The regional SEN link advisers should follow up the particular gaps/areas for development identified in this report, through their contacts with individual Local Authorities, in order to monitor progress.

2.   There should be local discussions within regions to establish which action points are best progressed at regional, subregional or individual Local Authority level. This will vary depending on demographic factors, existing strengths and local priorities.

Addressing the gaps:

Secondary mainstream school and post 16 inclusion:

3.   The DfES should strengthen its expectations of inclusive provision in *all* secondary mainstream schools. It should fund research into effective models of inclusion at this phase and identify/disseminate good practice. Consideration

should be given to the most effective ways of managing mainstream SEN units/resource bases for children with low incidence needs, so that these promote local inclusion and do not undermine the need to develop and improve universal provision.

4. The Government should implement the recommendations of the Little Report on provision for students with disabilities in FE colleges. This emphasises the need to organise funding to support and plan for better local opportunities within the mainstream FE sector. The LSC nationally should identify and promote positive examples of good practice, particularly in relation to those students with the most complex needs. In addition, greater consideration should be given to transport issues and the possibility of extended courses. Gaps in these areas tend to act as barriers to local provision for some students.

5. Regionally and subregionally, links should be made with local Learning Skills Councils, to start to plan improvements in practice and to develop the range of educational and vocational pathways that young people with low incidence needs can follow from 14 onwards. Provision should be planned more strategically, across the local FE sector, so that specialised courses for groups of students can be focused in particular colleges, where this is desirable and appropriate.

Transition planning:

6. The DfES and the Department of Health should review their overall approach to 14+ and 16+ planning, to ensure these are properly linked, that they encourage a more holistic person-centred approach and gives appropriate weight to longer-term issues. Further training and support should be provided as necessary through the existing Valuing People initiative. Positive approaches to involving young people in planning for themselves and supporting others with similar disabilities should be actively disseminated.

7. The DfES should provide a stronger lead to Connexions in supporting the transition process for young people with complex disabilities, and in ensuring that Connexions staff have the relevant skills and knowledge to do this.

8. At Local Authority level, agencies should work together with schools, parents and other relevant partners to ensure that all relevant information is shared across points of transition and is used by future providers.

Support for mental health issues:

9. The Department of Health should continue to support the CAMHS modernisation process and encourage new models of working. Particular attention should be given to the ways in which CAMHS can best be integrated within the new local Children's Services, to enhance and support their work. The Audit suggests that there is much to be gained by linking mental health workers to more frontline

support agencies (as well as providing consultancy support to professionals at Tier 3).

10. Regional Development Workers (CAMHS) should review the accessibility of existing CAMHS services to ensure there are no barriers for young people with disabilities. Active consideration should be given to reducing the need for specialist Tier 4 services, which currently require some young people with low incidence needs to attend provision a considerable distance from home.

11. Local CAMHS services should work more flexibly to ensure that support for mental health issues is available to all young people with low incidence needs who require such help.

Other therapy provision:

12. The Department of Health should continue to address recruitment issues (for example for Speech & Language Therapists). Strategic Health Authorities should work with Primary Care Trusts to ensure that there is sufficient capacity available to address needs locally. Local Therapy Services should be encouraged to make cost-effective use of their resources, linking with other partner agencies within the new Children's Services so that the best use is made of all the resources that are available.

Short break/respite care/extended day opportunities:

13. The DfES and the Department of Health should work together to extend the range of short break options for young people with low incidence needs and to disseminate good practice. In particular, the DfES should ensure that the development of extended day provision is inclusive of those with more complex difficulties (proper consideration is needed of transport and additional staffing issues).

14. The Department of Health should review the impact of its Direct Payments scheme to establish how far this has helped/hindered the development of more suitable short break/respite options.

15. Regionally and subregionally, a pool of suitable foster-placements should be developed. Foster-parents should be given the training and support needed in order to cater for young people with particular low incidence needs, and they should be properly remunerated for this complex task.

16. Local Authorities should work together and with the voluntary sector to provide a better range of social/leisure opportunities, that are more accessible to young people with low incidence needs and enable them to form relationships with others with similar disabilities, where this is what they would like.

17.   Local Authorities should review their short break/respite services, drawing on the views and experiences of parents and young people, to ensure there is a better range of options more closely linked to family needs.

Specialist staffing:

18.   The DfES and the Department of Health should monitor recruitment to and the availability of specialist posts for low incidence needs. Where there are shortages, it should liaise with Local and Strategic Health Authorities, and with training institutions, to develop alternative pathways or appropriate incentives.

19.   Regions should consult their Local Authority areas to establish whether there might be economies of scale or other service delivery benefits from regional/subregional management of some specialist services.

20.   Local Authorities should work with their specialist providers (such as Specialist Support Teaching Services) to ensure that existing patterns of staffing are best suited to the tasks that are required and are linked into a more integrated approach to service delivery.

Strategic planning

21.   Strategic planning is needed at regional, subregional and local levels. The balance will need to be decided within each region. However, it should take place within a clearly articulated national framework, linked to Quality Standards.

Standards

22.   There is currently a range of standards for provision and services (for example, within the SEN Code of Practice, Removing Barriers to Achievement, OfSTED, National Service Framework (Disabled Children), Every Child Matters and Quality Protects). The DfES should bring these together within a unitary framework[2] that is accessible to all relevant providers. The framework should be clearer in its principles and recommendations (in particular, the importance of provision being made locally wherever possible; and the value of a multi-agency approach to planning and delivery of services). It should cover desired outcomes (linked to Every Child Matters) as well as processes, and ensure that it encompasses all relevant services (including Health).

23.   The DfES should consider extending the existing standards for services for sensory-impairment (DfES 2002) to include a broader range of outcomes/service areas and a similar approach could be taken to other areas of low incidence need.

24.   SEN Regional Partnership coordinators/facilitators and other regional development staff should monitor and support the development of this Quality

---

[2] or extend NSF

Framework at individual Local Authority/Children's Service level. They should work to disseminate examples of good practice.

25. Local Authorities/Children's Services should set up a working group, involving a range of stakeholders (agencies, voluntary organisations, and parents) to decide how they will interpret and address the Quality Framework at local level, and to prioritise its application to particular 'risk groups'.

Audit/review/monitoring

26. The DfES should encourage the systematic and regular collection and analysis of information at local and regional level, regarding the needs and welfare of children and young people with complex needs, and their families. Such information should include education, health and social care data. Government Departments should link more closely together to ensure nationally-collected data is relevant and shared across all agencies.

27. The DfES should seek information, through discussion with regional and local bodies, OfSTED and its national advisers, about the continuing gaps/issues experienced in meeting the Standards outlined above, and this should be included in the focus for Joint Annual Reviews.

28. Each Region should establish a steering group involving relevant regional development/advisory staff, Local Authority and Strategic Health Authority managers and the voluntary/independent sector in order to audit/monitor progress, provide feedback/challenge/support to individual Authority areas where there are particular issues and identify areas where regional/subregional developments would be particularly beneficial.

29. Local Authorities should review their existing services for low incidence needs, against the nationally available Standards, drawing on the experience of a range of stakeholders, including parents/carers and young people themselves.

Development

30. The DfES should use this report as a basis for prioritising developments for low incidence needs. It should monitor progress over the next 5 years, in relation to the key gaps identified.

31. The Government should consider providing financial support for 'invest to save' initiatives within regions/individual Local Authority areas that will help strengthen local provision for low incidence needs, as an alternative to placements further afield.

32. Regional steering groups should have regard to the priorities identified and include these in their development plans. They should disseminate/share emerging

good practice, where there is evidence of significant progress in meeting low incidence needs or where there may be opportunities for generalisation to other parts of the country.

33. Regions should consider allocating some of their Regional Centre of Excellence funding to support the development of local capacity, linked to the priorities identified above. Regional working groups should also be consulted when the DfES is considering according specialist status to individual special schools within their area. Criteria for this decision should include the ability of the special school to make a significant impact on the development of capacity at the individual Local Authority level.

34. Individual Local Authorities/Children's Services should prepare development plans for improving services to young people with low incidence needs and their families. Plans should take account of the main priorities/gaps in service/ provision that have been identified through the national Audit and through any more local reviews.

Flexibility and collective responsibility

35. The DfES should support the movement of special schools towards more inclusive practice that is less defined by traditional categories. Through its advice and inspection arrangements, it should foster a more 'open' role where special schools are willing and able to adjust their provision to meet changing local needs and support the strengthening of local options, so that children do not need to be placed out of Authority.

36. The DfES should also encourage flexibility in the services and support provided by statutory agencies. It should support the development of joint accountability for outcomes (linked to the Quality Standards Framework).

37. Regional steering groups should work closely with their Local Authority areas to find ways of addressing current and future gaps in provision, drawing on cross-Authority initiatives and positive practice in individual Authorities/agencies.

38. Individual Local Authorities/Children's Services should consider the potential benefits of working together with other Areas, to promote greater consistency in good practice and mutual learning.

39. Individual agencies and services should give priority to collaborative working, particularly with those young people who present the biggest challenges and who are most likely to need a highly coordinated approach. Local Area 'Prioritisation Panels' appear to be an effective way of targeting local services and support on those young people/ families that are most at risk of out of Authority placement.

40. Voluntary sector and independent/non-maintained sector providers should follow the lead set already by organisations such as the RNIB, SENSE and the National Autistic Society, in seeking to develop their traditional emphasis on specialist provision in order to support the growth of more consistent local capacity across all regions of the country.

Regional Centres of Expertise

41. In our view, given the DfES's commitment within the Removing Barriers strategy to develop Regional Centres, there will need to be some clear investment in this direction.

42. One option would be to link RCEs to the programme already initiated to develop specialist special schools (where additional funding is already being made available). The problems with this option are as follows:

    (i) The programme currently links exclusively to schools providing for secondary-aged pupils

    (ii) There is not a clear linkage between the criteria used so far for identifying specialist schools and regional/individual Local Authority needs[3]

    (iii) The Audit has strongly indicated that developments are needed in *all* Authorities. RCEs need to be able to show clearly how they are supporting local developments/capacity (and that they have the skills to do so).

    (iv) Insofar as regional specialist provision *is* indicated, it needs to be for those pupils with the most significant/complex/challenging needs. The current criteria for according specialist status do not necessarily take level of severity of need into account[4].

43. An alternative low cost option would be to provide a small amount of money to each region to support/pump-prime improvements in local capacity for meeting severe/complex LI needs. Initiatives would have to demonstrate how they were going to address the key issues identified within the National Audit. They would need to be capable of extension across the region as a whole and ultimately be self-financing. They could include the development of (physical) centres, if this was consistent with both regional and local priorities, and the more systematic sharing of good practice across Local Authorities within the region.

44. The advantage of this model (apart from cost) would be in the flexibility available to each region to determine local needs and priorities (and ways forward). It could also strengthen links between regional and subregional/local planning. The main

---

[3] The distribution of specialist schools is currently very uneven across regions and categories of need.
[4] In the area of BESD, for example, there is some evidence to suggest that those schools with the most challenging pupils are most vulnerable when it comes to negative Ofsted inspections.

disadvantage to such a 'virtual' model is that it may not match the expectations of a 'physical entity' that 'regional centres' imply.

45.   A third option would be to draw together the development of specialist special schools and other LI initiatives within a more coordinated strategic regional planning framework. This could draw together a range of relevant stakeholders (SENRP facilitators, national SEN advisers, regional change advisers, local authority representatives, the voluntary sector) in identifying the priorities most likely to achieve local improvements. These could form the criteria against which 'specialist status' and funding of development initiatives could be allocated. This would be the option we would favour. It would link into the new structures and organisation within Regional Government Offices and could derive ongoing development funding from Regional Centres of Excellence budgets.

RESEARCH REPORT

1. INTRODUCTION

This section

- *Sets out the rationale and purpose of the National Audit of services, support and provision for low incidence needs*
- *Explains how 'low incidence needs' have been defined for the purpose of this review*
- *Emphasises the need for a holistic child-centred approach to assessing services and provision for this group of children, in the light of Every Child Matters*
- *Describes in broad terms the range of provision that Local Authorities typically make for children with low incidence needs and their families*
- *Provides a summary of the methodology used to carry out the Audit*

Rationale and purpose of the Audit

1.1 In its strategy for SEN and inclusion, 'Removing Barriers to Achievement', the Government indicated that it planned to carry out an audit of specialist services, support and provision for children and young people with low incidence needs. The rationale for this audit was as follows:

(i) Concerns have continued to be expressed by parents and some voluntary organisations about the availability and consistency of support provided across the country for pupils with low incidence needs (such as autism and multi-sensory impairment). The lack of suitable local provision means that the needs of some pupils may not be fully addressed or they may have to be educated in specialist settings at a significant distance from the family home.

(ii) Local authorities have expressed concern about the high costs of out of area provision, particularly residential placements in the independent/non-maintained sector. Many LEAs would also like to see pupils educated nearer to home, and to develop greater local capacity to provide for children who are currently placed elsewhere.

(iii) Some Local Authorities have reported significant difficulties in retaining specialist provision, skills and expertise for pupils with low incidence

needs because of a lack of 'economies of scale'. Smaller Authorities, for example, may only be able to employ one teacher for the visually impaired. In such areas, there may be restricted opportunities for the further development of specialist skills and limited cumulative experience of the needs of pupils with more complex and unusual difficulties (e.g. multi-sensory impairment).

1.2   The Audit was commissioned in order to:

(i)   Gain a picture of how Local Authorities meet the needs of children in their area with low incidence SEN and potential local and regional (and national) examples of good practice/expertise

(ii)   Explore the gaps in services, support and provision and how these gaps can be/are being addressed

(iii)   Use the above to support and inform policy and practice development for regional and local planning and provision, so that more pupils have their needs met locally, as well as informing the development of Regional Centres of Expertise[5]

1.3   In addition, the DfES has asked for advice on how any future audits of this sort might best be conducted and about potential approaches to reviewing progress.

1.4   The main emphasis of the Audit has been on identifying the gaps in provision and services, as they are currently organised and delivered, and on positive ways forward. While the Audit also provides a broad outline of the shape and form of existing provision and services, it is not intended to provide a detailed description of the way in which these are organised across the country. Although this might be a useful exercise, it is beyond the scope of this particular review.

Definition/meaning of 'low incidence'

1.5   The term 'low incidence' has wide currency within Education circles. It has been used, for example, in a number of Local Authorities as the basis for distinguishing between resources that should be centrally retained and those that should be devolved or delegated to schools. Because children with 'low incidence' needs are less common, their geographical distribution is more difficult to predict. It is also argued that meeting their particular needs requires specific skills and experience that are available only within specialised services and provision.

1.6   The term has typically been applied to children with sensory and/or physical difficulties, although autistic spectrum disorders (ASD) have more recently been included.

---

[5] Referred to in the Government's Removing Barriers to Achievement document

1.7   In determining the focus of the Audit, the DfES included other categories of need that are less common according to recent PLASC data returns[6] such as profound and multiple learning disabilities (PMLD). Severe behavioural, emotional and social difficulties (BESD) were also added. This group of children form a significant proportion of those who are currently placed out of Authority.

1.8   The categories included in the project specification were as follows:

1. multi-sensory impairments
2. severe visual impairment
3. severe/profound hearing impairment
4. profound and multiple learning difficulties
5. severe autistic spectrum disorders
6. severe behavioural, emotional and social difficulties

1.9   The above list exemplifies the fact that 'low incidence' is not a 'pure' concept. It is not simply a matter of 'rarity' as some physical/medical conditions have very limited significance, in terms of education/care/life chances. The definition needs to be more *functional*, with the emphasis on the complexity of the task of supporting and providing for the young person and the nature of the skills and organisation that are required to ensure that all their needs are properly addressed.

1.10   The notion of 'severity' is also important here. Sensory impairments in themselves are not uncommon or 'low incidence', either in childhood or later on in life, but they can have a significant impact when losses are severe, or where they are compounded by a range of other difficulties. Similarly, while teachers encounter a range of pupils presenting behavioural, emotional and social difficulties, there are a small number whose needs are so severe and complex that they present challenges, not just to schools but also to the range of professional agencies and support services that endeavour to provide for them.

1.11   In presenting a working definition of 'low incidence', particularly to other agencies less familiar with this term, the research team found it helpful to use a number of overlapping dimensions, as shown in Figure 1 (below). The types of need with which the Audit has been particularly concerned are those where there are overlaps across all 3 dimensions. It is in these circumstances that the task of meeting needs is particularly complex and challenging.

---

[6] Pupil-level annual schools census: this was extended in January 1995, so that head teachers are now required to provide data on all pupils on roll who have statements or are at school action plus, giving their primary need (against the 9 DfES categories).

Figure 1:   Towards an operational definition of 'low incidence' needs

RARITY

Phenylketonuria

? PMLD

ASD ?   Severe sensory/
              multi-sensory

Deaf

-        -   Severe ASD +
                  challenging behaviour

-

Severe BESD

SLD

Dyslexia

-        BESD

SEVERITY   **OUT OF AUTHORITY**
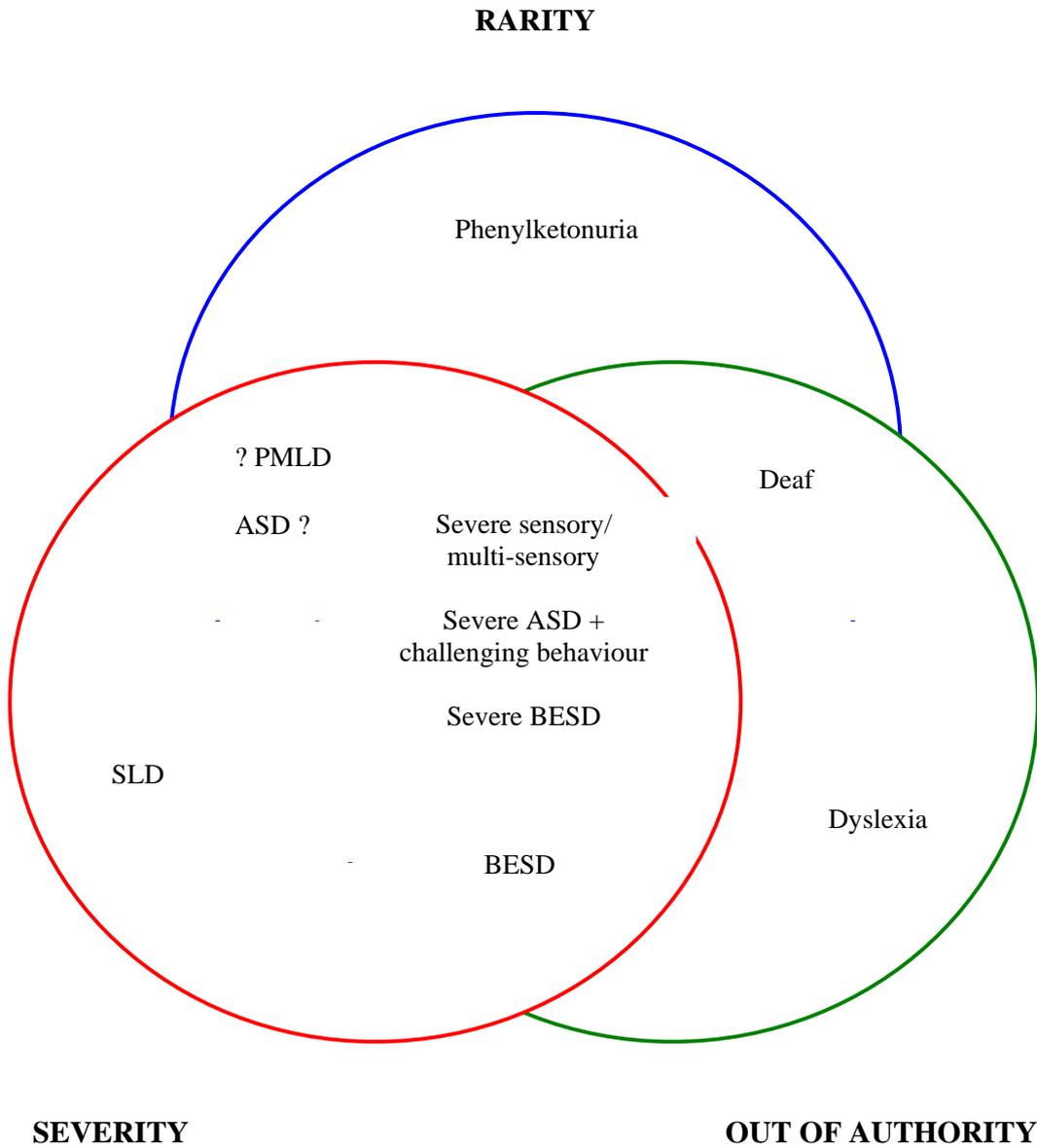
The need for a holistic approach

1.12 The Audit specification (see Appendix 1) required an approach that took account of the increasing national and local emphasis on developing more holistic provision for vulnerable young people and their families, exemplified by the creation of Children's Trusts and Children's Service Departments.

1.13 By contrast to some earlier reviews of this kind, the Audit therefore needed to focus not just on what is available for low incidence needs through the formal education system, but also on the range of other services provided through Social Services, Health and the private and voluntary sectors. Clearly a significant factor in making successful local provision for young people with complex difficulties is the degree to which the range of agencies work effectively together and draw on the full range of relevant knowledge and skills.

1.14 The Audit has been concerned not just with the narrower aspects of children's educational development, but with the broader outcomes outlined in the Government's policy ('Every Child Matters'). These include issues around care, safety, health, and wider aspects of social/economic participation.

1.15 The specification indicated a need to cover services and provision for the 2-19 age range. This implied a need for the Audit to include a range of stakeholders who work outside the period of statutory school age. It also suggested the importance of judging adequacy of services, support and provision against longer-term as well as shorter-term outcomes (for example, the ability to maintain positive effects across phase transitions, from preschool to school and from school to adulthood).

How local authorities typically provide for children and young people with low incidence needs

1.16 Generally, Local Authorities endeavour to maintain a continuum of provision. Educational placements range from support provided to children in mainstream settings, through to special school placements within/outside the Authority's boundaries. Table 1 (below) shows this range for the main types of low incidence needs covered by the Audit.

1.17 Less is known about the shape/form and organisation of services/provision in other sectors and the holistic approach to the Audit has enabled a broader picture. In terms of family support/advice and short break/respite care, most Authorities provide this for children with disabilities through their Children and Disabilities (Social Services) teams. These vary in the degree to which they have specialist posts (such as social workers for the deaf). Support for BESD tends to be through more generic social work support (for children in need or those in public care).

Table 1: Range of provision made for children with low incidence needs

	Sensory-impaired (hearing/visual)	Autistic spectrum disorders (ASD)	Behavioural, emotional and social difficulties (BESD)	Other LI needs (eg physical/medical difficulties)
Education support services	Generally, dedicated specialist teams	Varies, but increasing number of Authorities now have dedicated specialist posts/teams	Most Authorities have behaviour support teams, but size/scope varies Range of social inclusion projects linked to mainstream schools with higher levels of need	A few Authorities have dedicated advisory teachers for the physically-impaired Some use of outreach from special schools
Mainstream units/resource bases	More common for HI/deaf than VI Used less frequently now that more parents are preferring local mainstream school	Variation between Authorities (both in terms of availability of this kind of provision, and levels of complexity provided for)	Not a common form of provision, although some schools have on-site units for their own population (eg Learning Support Units, Nurture Groups)	Some Authorities have mainstream units or designated schools with better access/dedicated equipment/resources/staffing Used less frequently now that more parents are preferring local mainstream school
Maintained special schools	Some Authorities have their own dedicated special school for the deaf, or use such provision in a neighbouring area Rare for VI Children with more significant learning difficulties may attend other types of special school (MLD/SLD), with support as appropriate from external specialist support teams	Some Authorities have a dedicated special school for ASD. Most draw on a range of provision (m/stream, MLD, SLD special schools), depending on the child's level of learning difficulties Some MLD/SLD special schools have specific departments for ASD pupils	Most Authorities have one or more dedicated BESD special schools, but capacity, age range and balance of day vs residential places varies	Few Authorities still retain a dedicated special school for physical/medical needs, but some cross-Authority use is made of the provision that remains.
Independent/ non-maintained special schools	Varying use of this sector (both day and residential)	Most Authorities make some use of this sector (particularly on a residential basis, where there are respite/care issues; placements can be joint funded with Social Services and Health)	Most Authorities make some use of this sector, but significant variation in numbers. Again, used more for residential placements, where there are respite/care and control issues (can be jointly funded)	Varying use of this sector (both day and residential) More often where health care needs are very complex, or where children have profound and multiple learning disabilities and challenging behaviour

1.18   Therapy services (Speech/Physio/Occupational) vary in their levels of provision and sources of funding. Within speech therapy services, there can be some specialist posts linked to particular areas of need (eg deaf, autism, augmented communication).

1.19   Other types of service tend to be more generic/less differentiated for specific categories of need.

Overall methodology

1.20   According to the DfES specification, the Audit was expected to progress through 3 phases, with an initial stage of scoping the field, followed by development and piloting of the Audit materials, and then the Audit itself. This approach was adopted in broad terms by the research team. The scoping stage involved a review of the available literature, data and resources, along with interviews with key national stakeholders (see section 2 below). This was followed by a national questionnaire, sent to all 150 English Authorities, and a series of regional and subregional focus groups, including a wide range of participants.

1.21   Close links were established at an early stage with the DfES SEN Regional Partnership facilitators. This was for 2 main reasons: firstly, in order that they could be actively involved in the regional focus group discussions; and secondly, so that the research team could draw on their local knowledge and networks, to help maximise questionnaire return rates and stakeholder participation. In addition, it was felt that the SENRP facilitators would be in a good position to help take forward some of the key developments that might be outlined in the final Audit report.

1.22   The process in London was more complex because of the need to ensure close linkages between the Audit and a parallel study commissioned by the Association of London Chief Education Officers (ALCEO)/London Challenge (designed to look more specifically at out of Authority placements[7]). As the successful bidder for both projects, the Special Needs Consultancy was able to agree an integrated approach, which aimed to address both project specifications without placing unreasonable demands on Local Authority officers in the London region[8].

1.23   The DfES originally intended the Audit to start in September 2004 and finish in Spring 2005. In practice, the timescales had to be changed as a result of a delay in the final ratification of the project and an embargo on fieldwork during the General Election period.

---

[7] The key differences between the 2 projects related to the greater emphasis from ALCEO on detailed pupil data and on children going out of Borough (some of whom do not have low incidence needs). By contrast, the DfES national audit focused specifically on gaps in provision for low incidence needs, whether or not these led to out of Authority placement.

[8] A separate report on the London project (including perspectives gained through the National Audit) is being provided in parallel to ALCEO.

1.24   The questionnaire was finally issued in the middle of May and the regional/
          subregional focus groups took place in September/October 2005.

1.25   Further details of the methods and approaches adopted during each phase of the
          Audit are provided in Appendix 2. The key findings from each element of the
          Audit are summarised in the following sections.

2.   KEY MESSAGES FROM THE SCOPING PHASE:

This section

- *Outlines the main issues identified in interviews with stakeholders from the relevant central government departments, national associations and the key voluntary sector organisations*
- *Summarises the findings of the literature review, for each of the main types of low incidence needs*
- *Draws on other relevant data/resources made available, through contact with the SEN Regional Partnerships and the SEN National Advisory Team*

Scoping interviews

2.1   The scoping interviews provided a valuable orientation. They helped identify national issues and perspectives. They allowed some preliminary discussion of the research approach (in particular, the way in which 'low incidence' should be defined). They made links with related research and activities, and pointed to key references and other relevant data/resources. They helped identify appropriate people to invite to the regional/subregional focus groups, and some potential leads in terms of local/regional good practice.

(a) low incidence definitions:

2.2   The research team was reminded that 'low incidence' is not a term that has currency outside Education. The nearest equivalent in Health is 'low volume, high cost', but there is no similar expression in the field of social care. In this context, there was a need for a clear explanation of the focus of the audit, which other agencies could easily understand.

2.3   Generally, interviewees agreed with the ways in which 'low incidence' had been defined. There was support for the focus on the severe end of the continuum. However, a number of people pointed out that 'severity' was a relative term: not just in relation to functional 'cut-off' points, but also as a result of the interaction between children's difficulties and the provision available (see Wedell 1983 for an early discussion of this issue[9]). For example, 'severe ASD' might legitimately include 'more able' autistic pupils in mainstream secondary schools, who can experience significant difficulties when insufficient account is taken of their social and learning needs.

---

[9] This argument has been taken further by the social model of disability (eg Barnes, Rieser etc)

2.4　Other low incidence groups were also mentioned, such as those with complex medical/health care needs (including those with complex epilepsy), and young people within the BESD 'category' whose behaviour means they can present a significant risk to others (eg young sexual perpetrators)[10].

2.5　The view was expressed that national and local strategic planning should take greater account of changing patterns of incidence. On the one hand, some forms of sensory and physical impairment are being positively addressed by earlier medical interventions (cochlear implants etc). On the other hand, there is some evidence of a national increase in the numbers of children with significant ASD.

2.6　While a number of different types of need were identified, there was a general view that there was likely to be a significant overlap in some of the issues experienced.

2.7　Both within and between low incidence needs types, it was important to look at the individual child and his/her particular circumstances. Categories did not imply that 'one size fits all'.

(b) importance of a holistic approach:

2.8　Interviewees generally agreed that effective provision for children with low incidence needs required close cooperation between agencies: all relevant provision elements need to be in place.

2.9　With severe and complex needs, particularly when these are multiple, there are still significant risks of people 'passing the buck' and of children and families falling 'between the nets'.

2.10　There was positive endorsement for the new national inspection emphasis on joined-up working, but a concern that this should be more closely linked to processes and outcomes for individual young people.

(c) gaps in provision and services

2.11　A number of issues were raised by interviewees, which pointed to further investigation. It was argued that there are still significant inconsistencies in what is available across the country, but that there is increasing awareness of some of the differences (eg through national data such as the SEN Regional Partnership survey of out of Authority placements).

2.12　Issues were considered to be most challenging in the areas of provision for ASD and severe/complex BESD.

---

[10] In these circumstances, it is difficult to make use of traditional forms of 'group provision' and appropriate arrangements can be very difficult to achieve.

(d) regional centres of expertise:

2.13   Most interviewees felt that the main task was to build capacity at local level and that regional centres should be viewed in this context. They might be better seen as 'virtual': as networks of specialist advice, centres for specialist training, a focus for broader strategic planning; rather than a place where children were sent (such as a regional special school).

2.14   Independent/non-maintained school providers felt that they had a contribution to make, in providing for more complex needs and supporting local developments.

(e) key areas of difference:

2.15   While there was a good level of agreement in most areas, there were also some significant differences in perspective. In particular, representatives from the independent/non-maintained sector were more neutral about the use of out of Authority provision. Statutory agencies (and some national government bodies) wanted to see use of out of Authority provision reducing, as local capacity is improved.

2.16   Another key difference relates to the contribution of 'specialisms'. Some of those interviewed felt that low incidence needs would be met more effectively if there were a greater degree of specialism in services and provision. Others recognised the importance of specialist knowledge but were concerned to ensure frontline providers did not feel deskilled. In their view, what was needed were 'teams of people (local or regional) who know how to support families and young people, and who can take the 'scariness' out of each of the conditions for those who work with them'.

The literature review[11]

2.17   At a general level, low incidence needs fall along a continuum of severity, and there is evidence throughout the literature of the importance of early intervention and prevention, so that the potential impact of impairments and difficulties is reduced. There is an emphasis on working with a wide range of adults (parents, teachers and other frontline workers) to enhance their skills, as well as working directly with children.

2.18   For all the needs surveyed, there is a wide range of competing theories and intervention approaches, with both parents and professionals sometimes having their own particular preferences. This increases the challenges involved in working together collaboratively to ensure a consistent approach.

2.19   Some of the more intensive interventions (particularly those related to pupils with severe autistic spectrum disorders) can be very costly, and this presents issues

---

[11] See Appendix 3 for full version of the review

where the evidence base is uncertain and where individual parents are strongly committed to them.

(a) Severe sensory/multisensory impairment:

2.20 The literature points to the fact that people with sensory impairments are increasingly being recognised as a cultural minority, whose experience can be very different from people whose vision or hearing is relatively unimpaired.

2.21 Over recent years, this has led to a stronger emphasis, among the deaf community, on deaf identity issues[12]. There has been an associated (and long-standing) debate about the need to recognise signing as a language in its own right. Increasing concerns have been raised about the potential isolation of deaf pupils from others with similar cultural and language identities. A greater level of importance has come to be attached to creating opportunities for deaf children to learn and socialise together. This raises a number of issues for traditional models of integration, which tend to be challenged by some professionals and some members of the deaf community as 'assimilationist'.

2.22 With regard to visual impairment, cultural identity issues are less strongly defined. However, the literature raises continuing concerns about the level of ability of the 'sighted world' to understand the problems experienced by blind and partially-sighted people and their particular needs. The infrequent occurrence of severe visual impairments in children means that specialist skills, knowledge and expertise must be safeguarded, so that pupils' learning, emotional and social needs can be properly addressed.

2.23 A number of children with sensory difficulties have multiple impairments. The issues for those with multisensory difficulties are quite well covered in the literature (although definitional considerations remain). Various authors emphasise the importance of skills training and awareness-raising for the variety of front-line professionals. However, there is also a wider population of children with sensory impairments who present other challenges, such as severe learning difficulties, physical/medical needs and autism. The issues for these groups are less well-documented. Overall, there is a concern that such pupils should not be excluded by the narrower remit of disability-specific services. It is important that all relevant services (and schools/other educational establishments) work together to meet each child's individual needs.

2.24 The literature review shows recent commitment by Government to identify 'quality standards' for services to sensory-impaired pupils. While this is to be welcomed, there is some evidence that standards have not yet been framed holistically, in a way that encourages a 'joined-up' approach[13].

---

[12] There continues to be some debate about the link between this and the broader disability discourse (see DRC 2002 and elsewhere)

[13] There has been a greater emphasis on this in the Early Years (through the Government's ESPP initiative)

2.25 Continuing concerns are raised by a number of commentators about problems experienced by children with sensory impairments and their families in accessing a range of services. In particular, families have limited access to short breaks/ respite as a consequence of the emphasis of this provision on children with broader learning disabilities. And there are limited opportunities for some children, particularly in adolescence, to have appropriate support for their emotional/mental health needs.

(b) Severe autistic spectrum disorders:

2.26 With regard to ASD, the literature points to significant issues around diagnosis. The importance of early intervention is recognised but there is wide variety in procedures and processes for identification and assessment. These can mean delays in providing appropriately for individual children's needs.

2.27 The importance of family support is recognised, to understand the implications of autism and to help deal with some of the accompanying social/behavioural issues. Authors point to the value of early practical training for parents in teaching skills and managing problem behaviour.

2.28 It is recognised that some children's behaviour can present significant challenges, leading to increasing isolation for children and families, and risk of family breakdown. A number of children with severe ASD currently need to be placed residentially, sometimes a long way from their family home.

2.29 The literature points to the importance of good interagency communication, and the need for a consistent and concerted approach.

2.30 A range of effective methods/techniques is now available to help improve children's social communication. These are becoming more generally accessible, through provision in a range of settings. A number of interventions have been put forward that are more intensive (for example, Son Rise, Daily Life Therapy and Lovaas). These are not routinely available: parents who favour them are prepared to commit themselves and others to a heavy and costly programme of intervention, and to take their children long distances (within and outside the UK) in order to have access to them. There continues to be debate nationally and internationally about their effectiveness, and a need for further research.

2.31 The literature highlights a number of gaps in provision for children with ASD. These include issues in making appropriate provision post 16 and difficulties in accessing suitable short break/respite opportunities. The latter relates partly to access threshold issues (see above), particularly for 'more able' autistic children or those with Aspergers' syndrome. There are also issues for some children and parents around the social mix in residential units (where the majority of young people may have significant learning disabilities). In addition, some children with

severe ASD are more at risk of being excluded from respite care provision, because of their challenging behaviour.

2.32 The literature describes a number of emerging alternatives for short break/respite care, including specialist fostering schemes and disability-specific care services.

(c) Severe BESD (behavioural, emotional and social difficulties):

2.33 A range of authors point to the significant definitional problems surrounding this group. Many argue that behaviour is contextual and that perceptions of its significance are relative. Although there have been attempts in the past to categorise children with BESD into 'types' ('disaffected', 'disturbed' etc), the boundaries between these remain extremely blurred.

2.34 There is also increasing recognition that school ethos has a significant effect on pupil behaviour, not just for the generality of pupils, but also in improving the outlook for those most at risk. High levels of demand from schools for external agency support for individual pupils can mean that some young people with more significant emotional/mental health needs can be missed.

2.35 The literature again points to the importance of prevention/early intervention, both through practice in schools and a range of other more community-based initiatives (such as SureStart).

2.36 It is recognised that, even with effective early intervention/prevention, there may still be a number of young people with very significant needs, who remain highly vulnerable within the current system. These young people need particularly effective and coordinated planning across all relevant agencies, with a named keyworker who is able, whatever the difficulties, to act as an advocate and support their continuing social inclusion.

2.37 A number of these young people have traditionally been part of the 'care system'. There is evidence from the literature of some improvements in the education and care experience of 'looked after' children, but there is still a long way to go.

2.38 For those young people with significant mental health needs, there is a wide variation in the extent and quality of services available. A series of national reports have emphasised the need for improvement and for stronger connections between CAMHS (child & adolescent mental health services) and other related agencies.

(d) Other low incidence needs:

2.39 The literature confirms that a number of the issues experienced by the groups identified above are common to a range of other categories of low incidence need. In addition, children with complex health care needs require close cooperation

between hospital and community services. The quality of the physical environment for children with physical/medical needs is also a major issue, with significant space issues for some families, relating to the accommodation available.

Evidence from other data/resources

2.40 Other resources referred to at this stage included the work of the SEN Regional Partnerships and relevant sections from the SEN National Adviser visits to all English LEAs that took place during 2004-2005.

2.41 The SENRPs have collected data on use of out of Authority placements for the last 4 years. The data for 2004 showed that the highest use of such placements related to children with BESD, followed by Autism. A similar picture is shown by the 2005 data, which has recently been published.

2.42 The SENRP data showed a significant variation in use of out of Authority placements across the country, with less use in the West and East Midlands, Yorkshire and Humberside and in the Eastern region, and more in London and the SE, and in the North-West[14].

2.43 The National Adviser reports provided an insight on the ways in which individual local authorities are attempting to build local capacity and on the issues they continue to face in meeting the full range of needs. On the positive side, a number of Authorities are beginning to re-focus their own special school provision on children with more complex needs. There is greater joint decision-making across the range of relevant agencies, and a stronger motivation to look at creative and more flexible local ways of meeting individual needs. On the negative side, Advisers report capacity issues in some Authority areas, pressure to react to individual SEN Tribunal decisions, continuing shortfalls in the availability of respite for parents/families and difficulties in managing overall expenditure.

---

[14] Overall average was 82.55 places per 100,000 population (0-19). The picture for 2005 remains broadly similar

Key points from the Scoping Phase:

1) *General agreement with the working definition of 'low incidence' and the need to focus on the severe end of the continuum*
2) *Biggest challenges in meeting the needs of children with severe/complex ASD and those with significant BESD*
3) *Need to maintain existing good quality services and provision, which reduce the potential impact of some low incidence needs*
4) *Considerable variation (as well as similarities) within each category of needs: services/provision should be responsive to the needs of individual children /families and their particular circumstances*
5) *Need for the Audit (and Ofsted) to look not just at specific services/types of provision, but how these link together to meet complex individual needs*
6) *Differences in view about the ongoing need for out of Authority provision and about the role/contribution of 'specialist knowledge': significant variation between Authorities across the country in their use of the independent/non-maintained school sector*
7) *Range of competing theories and intervention approaches, which present challenges for parents/carers and professionals in collaborative working and adopting a consistent approach*
8) *Importance of meeting all aspects of children/families' needs: shortfalls in one area can hamper local provision, even when other elements are in place*
9) *Evidence from the literature of gaps in mental health/social care support, and in FE/post 16 opportunities*

3. QUESTIONNAIRE FINDINGS:

> *This section*
>
> - *Describes the questionnaire sent to the 3 main statutory agencies (Education, Health, Social Services) in each English Local Authority area*
> - *Reports on the key findings for each of the main types of low incidence need*
> - *Summarises the elements of provision that are seen to be important and mostly in place*
> - *Summarises the key gaps in support, provision and services*
> - *Identifies the service areas that are considered to be most in need of development*

3.1 The questionnaire focused on the 3 main types of low incidence needs identified at the scoping stage (severe sensory/multisensory impairment; severe autistic spectrum disorders; severe behavioural, emotional and social difficulties). Additional space was provided at the end of the questionnaire so that respondents could register issues presented by other types of need.

3.2 The questionnaire was sent to the 3 main statutory agencies (Education, Health, Social Services) in each English Local Authority area.

3.3 The key questions covered in the questionnaire were as follows:

1) What elements of provision are considered important for children with the different kinds of low incidence needs ?

2) What are the major gaps in services, support and provision (at local/regional/ national level) ?

3) What are the key areas for development that will help address these gaps ?

3.4 Further details on the questionnaire design, content and process are provided in Appendix 2 of this report.

3.5 Key findings are reported for each of the three main types of need in turn.

SEVERE SENSORY/MULTISENSORY IMPAIRMENT:

3.6 The elements of provision listed in the questionnaire were generally regarded as important by all 3 agencies. The highest level of support was for 'early identification and intervention' (95% of respondents agreed this was important).

The lowest level was for 'suitable transport arrangements' (ticked by 85% of respondents).

Provision mostly in place

3.7 The elements of provision needed by this group were generally regarded as 'mostly available' or 'available to some extent' (average availability ratings ranged from 1.78 to 3.08[15]; see Graph 1.1 below).

3.8 The highest availability rating was for 'early identification and intervention', suggesting that this important practice is generally well in place. Ratings also suggest that the following are also well-established in most Authorities, for this type of low incidence need:

- Multi-disciplinary assessment
- Specialist preschool support in the home
- Skilled practitioners with training/experience in this kind of need
- Specific medical interventions (such as cochlear implants)
- Positive and inclusive staff attitudes
- Specialist equipment
- Technology (for example, to enhance residual hearing/vision)

Gaps in provision[16]

3.9 The element rated as least available was '*a suitable range of short break/respite opportunities*'. Given that this was generally ticked as important, it appears to be one of the biggest issues to address for children with this type of needs.

3.10 Combining 'importance' and 'availability' ratings provided a clearer picture of the elements that respondents felt were most in need of development[17]. The biggest gaps identified for this group were '*short break/respite opportunities*', '*suitable range of 14-19 opportunities*' and '*specialist careers' advice*'.

3.11 There was some evidence of differences in perspective between the 3 agencies. The biggest differences in importance/availability ratings were in relation to 'effective management of transitions' and 'opportunities for collaborative learning and socialisation with peer groups with similar impairments' (which Education respondents rated higher).

---

[15] (1 = completely available; 5 = completely unavailable)

[16] Key gaps are written in italics in the text

[17] Items ticked as important were given a score of 1 and this was multiplied by the respondent's availability rating for that item. Items not ticked were scored as 0 – leading to a zero composite score for any item not ticked, even if it was unavailable.

Graph 1.1: Severe/Profound Sensory Impairment: Combined importance/availability ratings (elements of provision):
(score of 2 = important + mostly available; 3 = important + available to some extent; 4 = important but mostly unavailable; 5 = important but completely unavailable)
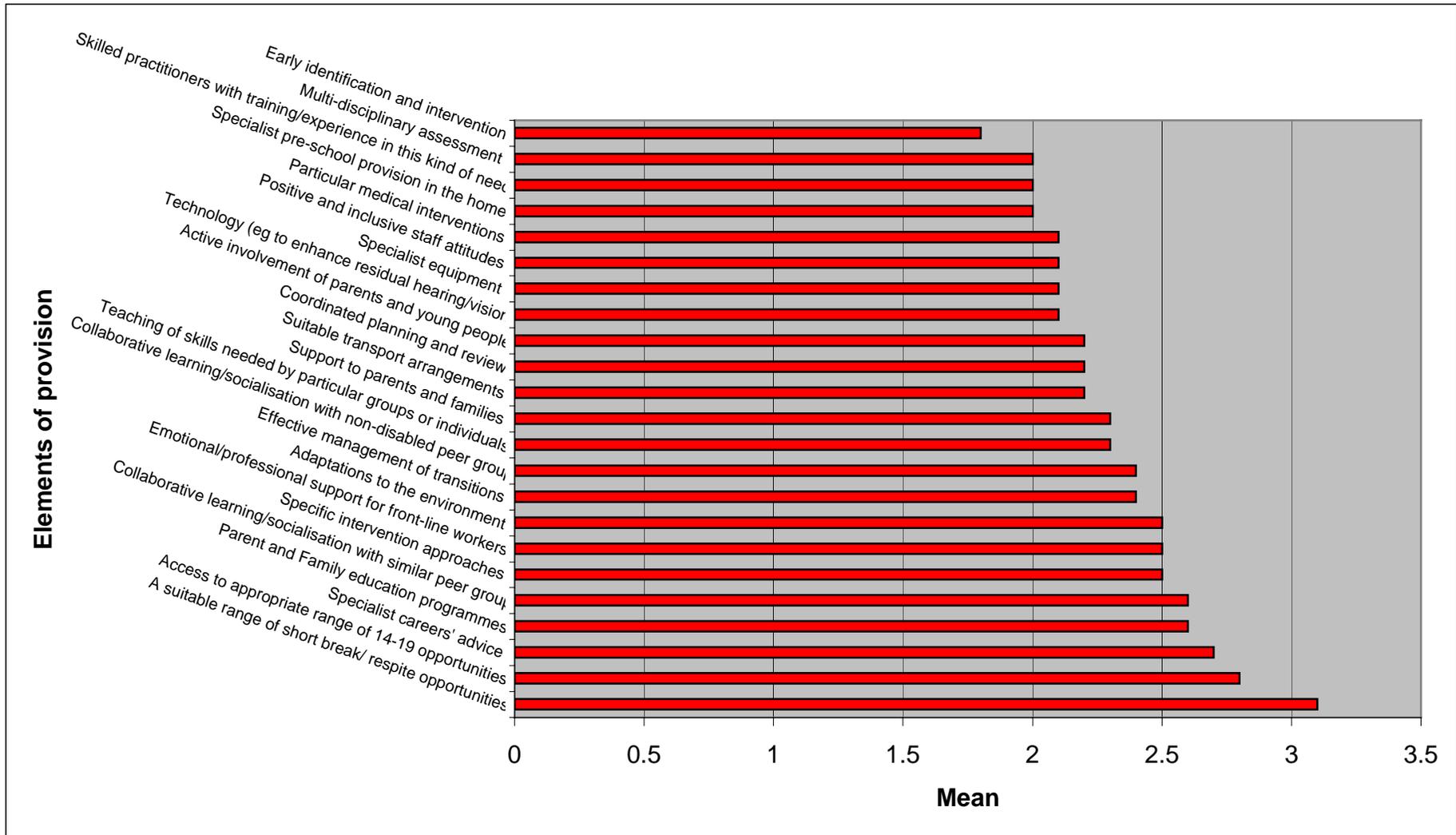
Graph 1.2: Severe/Profound Sensory Impairment: Priority gaps in provision (elements):

Graph showing the number of respondents selecting these elements as insufficient and capable of making the most significant difference in severe/profound sensory impairment

X-axis (Elements of provision), left to right:
Particular medical interventions; Specific intervention approaches; Technology; Suitable transport arrangements; Specialist pre-school homecare; Specialist equipment; Positive staff attitudes; Support for front-line workers; Early identification & intervention; Active involvement of parents etc; Collaboration w. peer group; Teaching of skills; Support to parents and families; Collaboration w. non-disabled peers; Multi-disciplinary assessment; Skilled practitioners; Adaptations to ...; Parent ...; Specialist careers' advice; Coordinated planning & review; Short break opportunities; Effective management of transitions; Range of 14-19 opportunities

3.12 However, the size of differences between agency responses for this type of needs was generally quite small. The main variation can be explained by the tendency for Education respondents to rate provision as more available than their Health and Social Services counterparts.

3.13 Generally, responses were similar across the regions. The main differences were in relation to 14-19 provision and short break/ respite opportunities (rated as bigger gaps in parts of London (West/South East) and the Eastern region but less of an issue in the North East and South East).

3.14 Respondents were asked to identify the 3 elements from the questionnaire list (or others nominated by them[18]), where they felt improvements/greater availability would make the most significant difference to meeting the needs of this group. Graph 1.2 shows the profile of responses. Improvements in *access to 14-19 opportunities*, *short break/respite*, *transition processes* and *coordinated planning/ review* were the most frequently selected.

3.15 There were some differences in agency priorities. Education and Health tended to place greater emphasis on short/break respite opportunities than Social Services respondents. There were more mentions by Education respondents of the need for better specialist careers' advice and opportunities for collaborative learning/ socialisation with similar-disabled peers. Health placed greater importance on the need for skilled practitioners; Education and Social Services more on parent and family education programmes.

Service/provision areas needing development[19]

3.16 Respondents were asked to indicate the extent of development needed in a range of service/provision areas. For sensory/multisensory impairment, average ratings for different items ranged from 2.55 to 3.89, indicating that services/provision needed a little (2) to some (4) development[20] (see Graph 1.3). Areas where the biggest need for developments was indicated were: both *mainstream FE* and *specialist post 16* provision, *secondary mainstream, CAMHS* and *other therapy services*. The lowest need for development was seen to be in the area of school age special school provision[21].

3.17 There was a broad similarity between the perspectives of different agencies, with no clear evidence of either 'crossover' (agencies thinking others needed to develop more than them) or 'parochialism' (agencies being particularly concerned about their own shortfalls). Any differences were largely due to Health seeing a greater need for

---

[18] A number of other elements were suggested by a small number of respondents. These mainly related to the need for specific specialist posts and effective arrangements for staff training, recruitment and retention.

[19] It is important to note here that 'low need for development' does not necessarily imply that a particular type of provision/service is unimportant – it may simply be that it is already in place and makes an adequate contribution.

[20] 1 = no development needed; 5 = much development needed

[21] A number of other developments were suggested, mainly focusing on the need to extend multi-disciplinary working from Early Years into school age and beyond.

development across the range of service/provision areas. The biggest variation was in the area of *voluntary/community support*, which Social Services rated more highly.

3.18   Again, there was broad similarity across the regions. The main differences were in the area of 'secondary mainstream', where the biggest issues seemed to be in Merseyside, the Eastern region, and Yorkshire and Humberside (lowest need for development reported in the South East); in 'special school provision for sensory-impaired' (low need for development in most regions, but higher in parts of London, the Eastern region and Merseyside); and 'CAMHS' (frequently mentioned in most regions, but less in the East Midlands and South East).

3.19   Respondents were asked to nominate the three key service/provision areas where they thought developments would make the biggest difference in meeting the needs of this group. Graph 1.4 shows the profile of responses. *CAMHS* and *other therapy services* were nominated most frequently, with *post 16 provision* (mainstream FE and specialist), *early years*, and *foster-parents* also receiving a high number of nominations. Social Services tended to mention developments in *youth service* provision and *voluntary/community support* more frequently than the other two agencies.

Confidence in capacity to meet needs

3.20   Respondents were asked for two sets of ratings: one for their own confidence levels, for this group, and one giving their view of parents' confidence levels[22].

3.21   Responses suggested that agencies were quite (2) to moderately (3) confident themselves (mean = 2.63). They saw parents as being only slightly less so (mean = 2.93). Agency comparisons suggested that Education respondents were slightly more confident in their local capacity to meet the needs of this particular group than their Health and Social Services counterparts.

---

[22] 1 = very confident; 5 = not at all confident

Graph 1.3:   Severe/Profound Sensory Impairment: Need for development ratings (service/provision areas):
(score of 2 = little development needed; 3 = average amount needed; 4 = some needed; 5 = much needed)
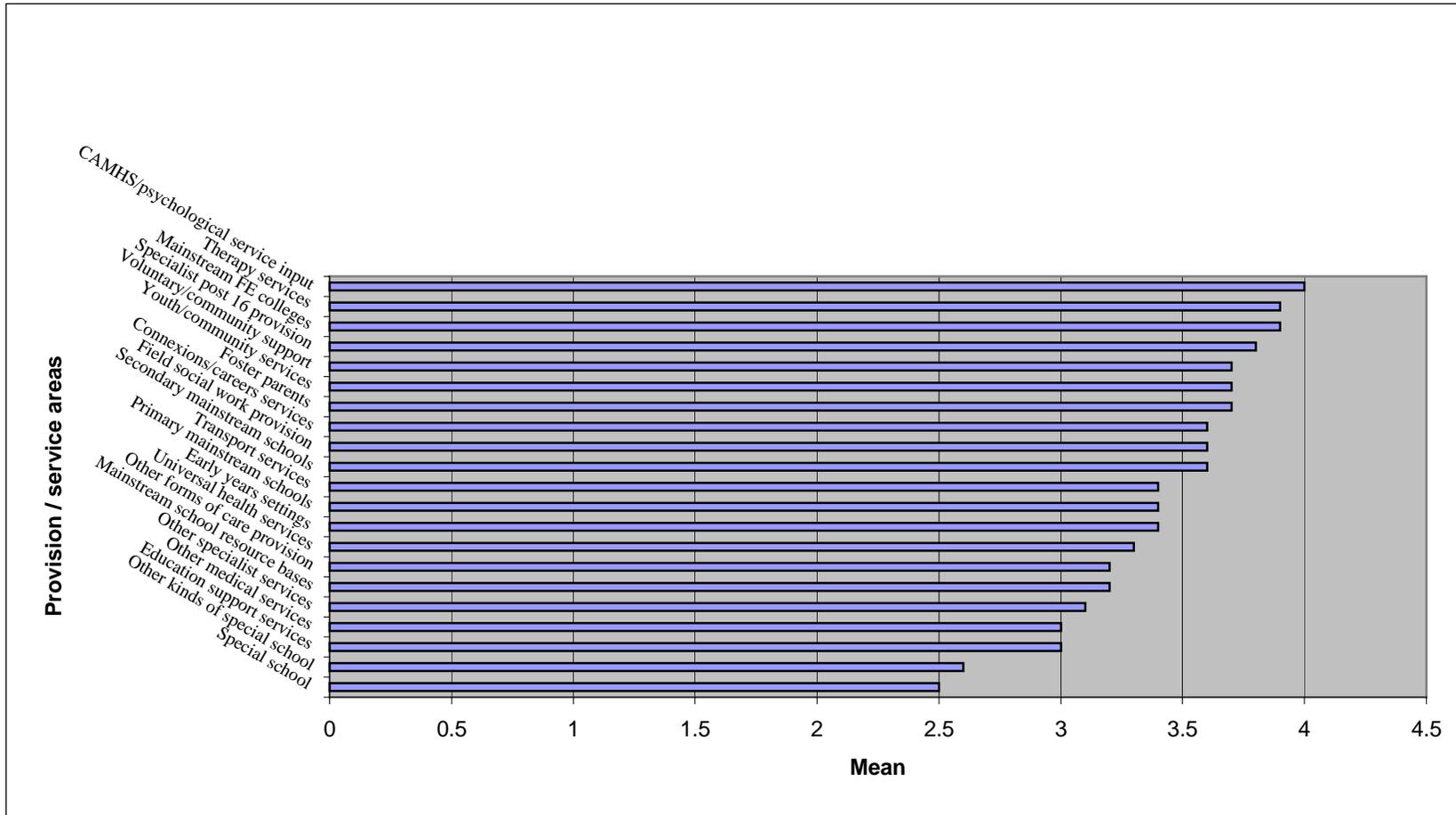
Graph 1.4: Severe/Profound Sensory Impairment: Priority areas for development (services/provision)

Graph to show the number of respondents selecting these areas as the site where developments would make the most significant impact on meeting the needs of children/young people with severe/profound sensory impairment
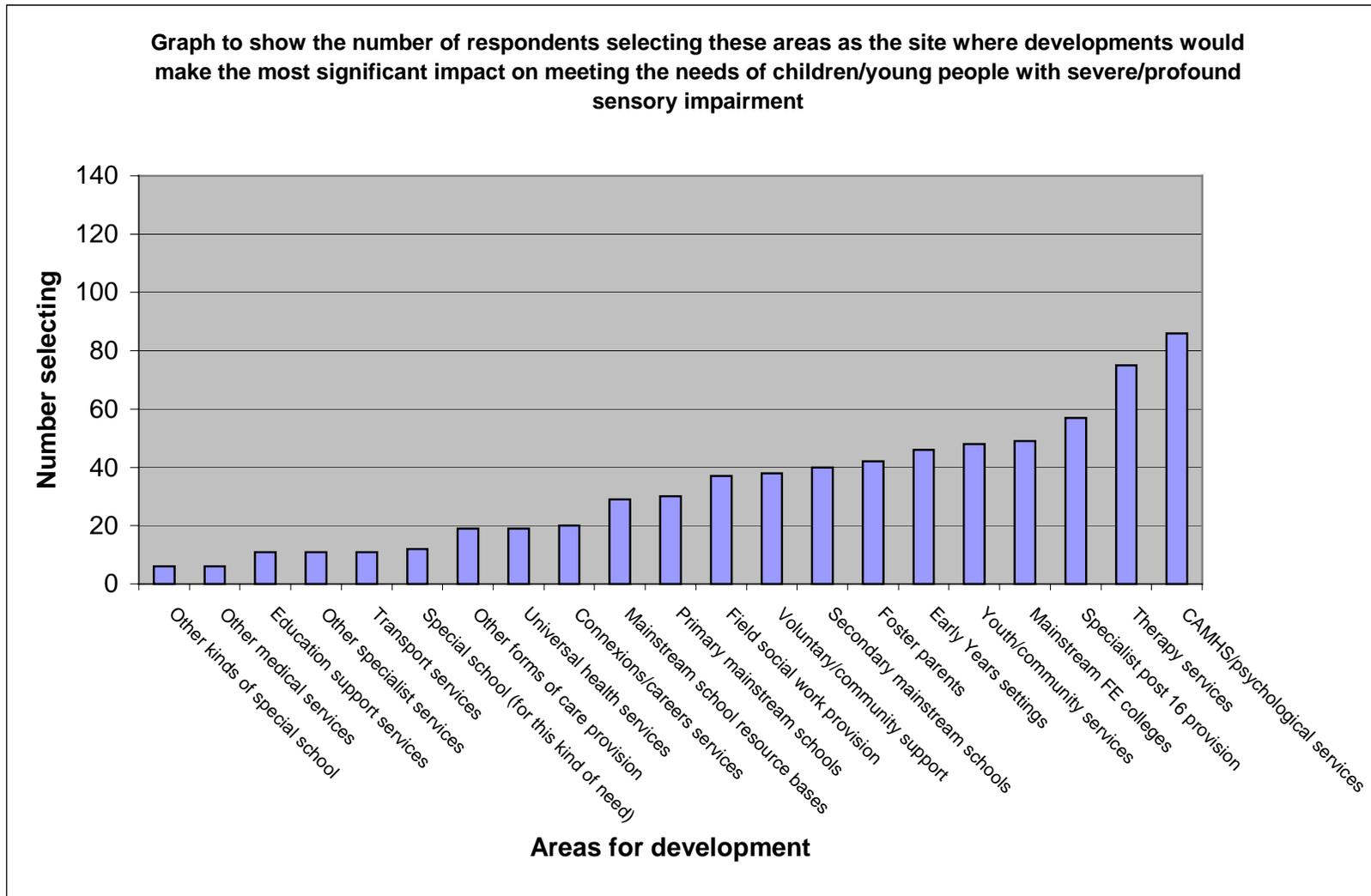
SEVERE AUTISTIC SPECTRUM DISORDERS (ASD):

3.22 The elements of provision listed in the questionnaire were generally regarded as important by all three agencies. The highest levels of support were for 'early identification and intervention', 'multi-disciplinary assessment' and 'coordinated planning/review' (95% of respondents agreed these were important). The lowest level was for 'prescription and monitoring of medication' (ticked by 75% of respondents).

Provision mostly in place

3.23 The elements of provision needed by this group were generally regarded as 'mostly available' (2) or 'available to some extent' (3) (average availability ratings ranged from 2.21 to 3.27 (see Graph 2.1 below). Availability ratings were slightly lower than for the sensory/multisensory area.

3.24 The elements rated highest, in terms of availability, were:

- early identification and intervention
- multi-disciplinary assessment
- access to information
- ASD- specific teaching approaches

suggesting that these important elements of good practice are more generally in place.

Gaps in provision

3.25 The elements rated as least available were *access to appropriate 14-19 opportunities*, *family keyworkers*, *support for mental health issues* and a *suitable range of short break/respite opportunities*. Given that these elements were generally ticked as important, they appear to be some of the biggest issues to address for children with this type of needs.

3.26 When responses for 'importance' and 'availability' were again combined, the biggest gaps identified were *'access to a suitable range of 14-19 opportunities'*, *'family keyworker'* and *'suitable range of short break/respite opportunities'*.

3.27 There was greater similarity in perspective between the three agencies for this type of need. Again, variations were generally due to a slight tendency for Education respondents to rate provision as more available than their Health and Social Services counterparts.

3.28 Generally, responses were similar across the regions. The main differences were in relation to 'support for mental health issues' (rated as a bigger gap in the Eastern region, the East Midlands and Merseyside – less of an issue in parts of

London) and 'access to supported social/leisure activities' (similar picture: most availability in the London North Central subregion).

3.29 Respondents were asked to identify the three elements from the questionnaire list (or others nominated by them), where they felt improvements/greater availability would make the most significant difference to meeting the needs of this group[23]. Graph 2.2 shows the profile of responses. Improvements in *support for mental health issues*, *range of short break/respite opportunities*, *family keyworkers*, *supported social/leisure opportunities* and *behaviour management support* were the most frequently selected.

3.30 Agency priorities were broadly similar for this group. However, a number of respondents across all three agencies emphasised the need for a multi-agency approach to the way in which support is actually delivered.

Service/provision areas needing development

3.31 Respondents were again asked to indicate the extent of development needed in a range of service/provision areas. For severe ASD, average ratings for different items ranged from 2.92 to 4.38, indicating that services/provision needed a higher level of development (typically, an average amount (3) to some (4) - see graph 2.3). Areas where the highest ratings were given were: both *mainstream FE* and *specialist post 16* provision, *secondary mainstream* schools, *foster-parents*, *CAMHS* and *other therapy services*, and *youth service + voluntary/community support*. The lowest need for development was seen to be in the area of school age special school provision[24].

3.32 There was a broad similarity between the perspectives of different agencies, though Social Services tended to give lower ratings than Education and Health to the need for developments in field social work and other forms of care provision than fostering.

3.33 Again, there was broad similarity across the regions. The main differences were a matter of degree. In terms of *secondary mainstream*, the biggest issues seemed to be in some parts of London; for *CAMHS/clinical psychology input*, in the Eastern region/Merseyside; and for *transport arrangements*, in Eastern, South Central and Yorkshire/Humberside.

---

[23] A number of other elements were suggested by a small number of respondents. These were mainly more specific examples of elements already listed in the questionnaire.

[24] A number of other developments were suggested, mainly focusing on the need to build local capacity to avoid young people with severe ASD having to go residentially a long way from home as they progressed to adulthood.

Graph 2.1: Severe Autistic Spectrum Disorders: Combined importance/availability ratings (elements of provision):
(score of 2 = important + mostly available; 3 = important + available to some extent; 4 = important but mostly unavailable; 5 = important but completely unavailable)
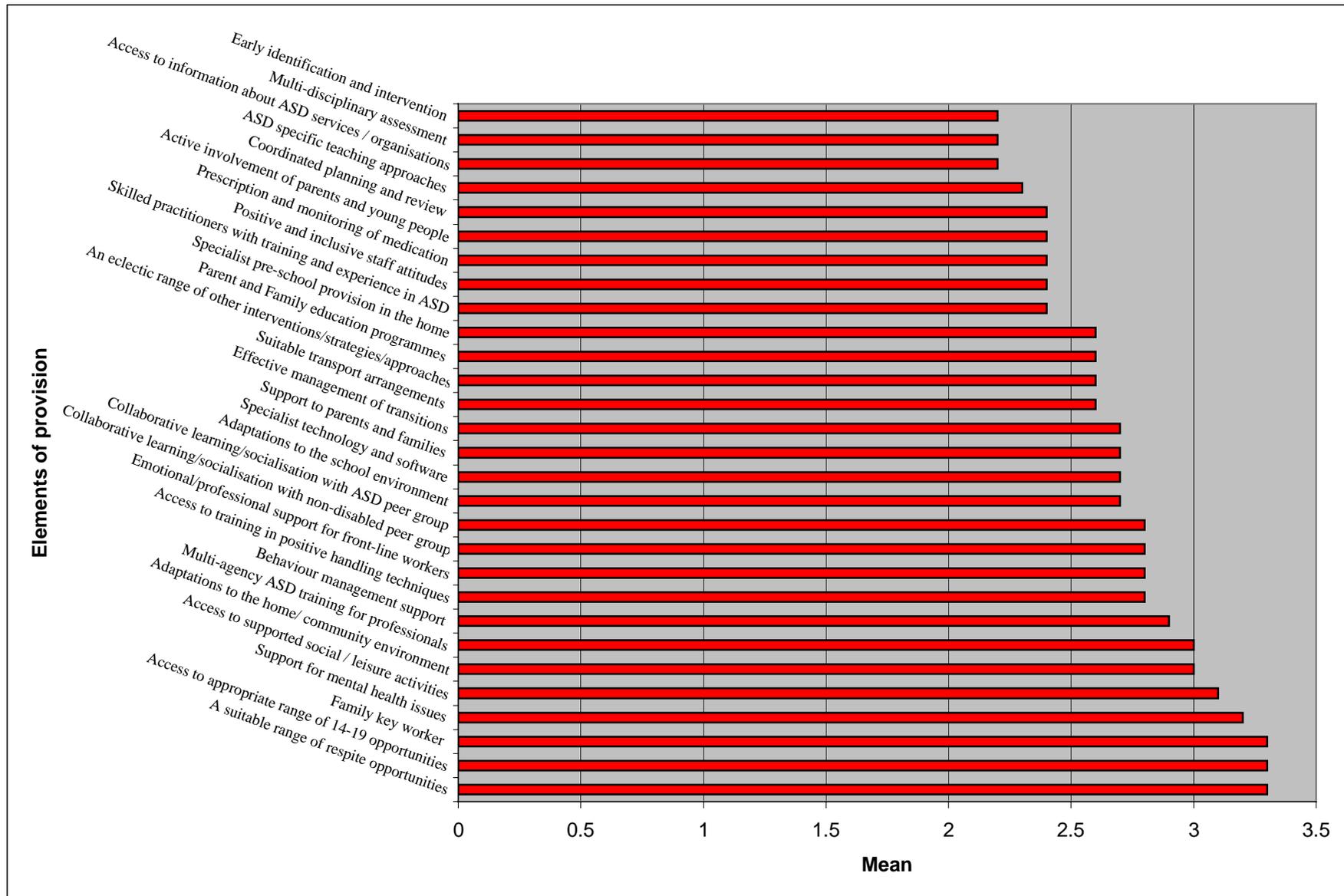
Graph 2.2: Severe Autistic Spectrum Disorders (ASD): Priority gaps in provision (elements):

Graph showing the number of respondents selecting these elements as insufficient and capable of making the most significant difference in autistic spectrum disorders

Number selecting (Y-axis: 0 to 70)

Elements of provision (X-axis):
- ASD specific teaching
- Access to info about ASD services
- Suitable transport arrangements
- Range of interventions / strategies
- Adaptations to school
- Support for front-line workers
- Adaptations to school
- Prescribing & monitoring medication
- Involvement of parents & youth
- Specialist pre-school homecare
- Training in positive handling
- Range of 14-19 opportunities
- Support to parents and families
- Multi-disciplinary assessment
- Positive & inclusive staff attitudes
- Multi-disciplinary assessment
- Collaboration w. peer group
- Parent and Family education
- Skilled practitioners
- Early identification & intervention
- Collaboration w. non-disabled peers
- Coordinated planning and review
- Multi-agency ASD training
- Specialist technology and software
- Behaviour management support
- Supported social / leisure activities
- Family key worker
- Range of respite opportunities
- Support for mental health issues

3.34 Respondents were asked to nominate the three key service/provision areas where they thought developments would make the biggest difference in meeting the needs of this group. Graph 2.4 shows the profile of responses. *CAMHS* was by far the most frequently nominated area, with *secondary mainstream schools*, *therapy services + clinical psychology inputs*, and *forms of care provision (other than fostering)* also receiving a high number of mentions. Again, Social Services tended to mention developments in *youth service* provision and *voluntary/ community support* more frequently than the other two agencies.

Confidence in capacity to meet needs

3.35 Responses suggested that agencies were moderately (3) confident themselves (mean = 3.02) in their capacity to meet this type of needs. They saw parents/carers as being only slightly less so (mean = 3.21). Agency comparisons again suggested that Education respondents were slightly more confident than their Health and Social Services counterparts

Graph 2.3:   Severe Autistic Spectrum Disorders: Need for development ratings (service/provision areas):
(score of 2 = little development needed; 3 = average amount needed; 4 = some needed; 5 = much needed)
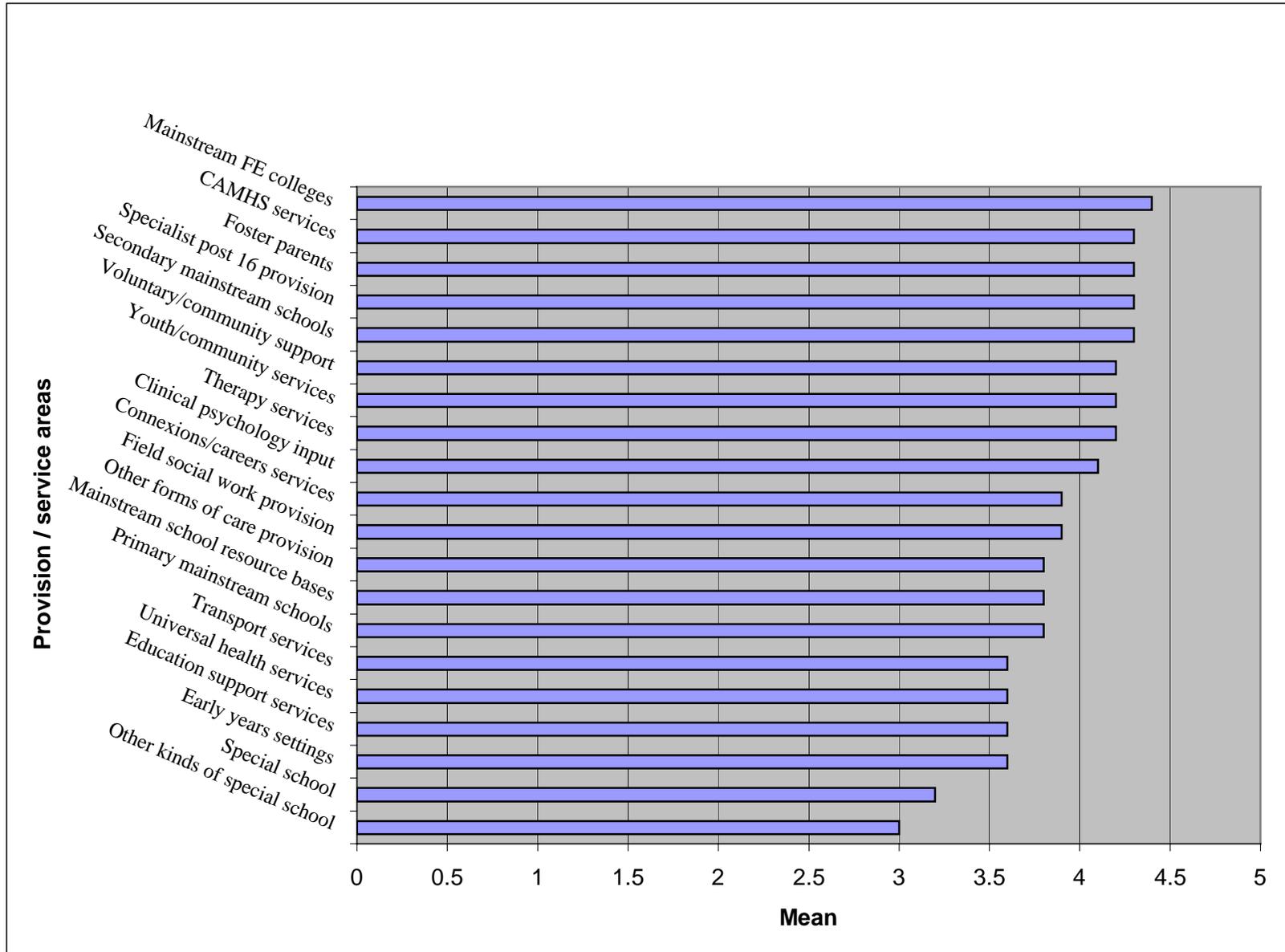
Graph 2.4: Severe Autistic Spectrum Disorders: Priority areas for development (services/provision)

Graph to show the number of respondents selecting these areas as the site where developments would make the most significant impact on meeting the needs of children / young people with severe autistic spectrum disorders
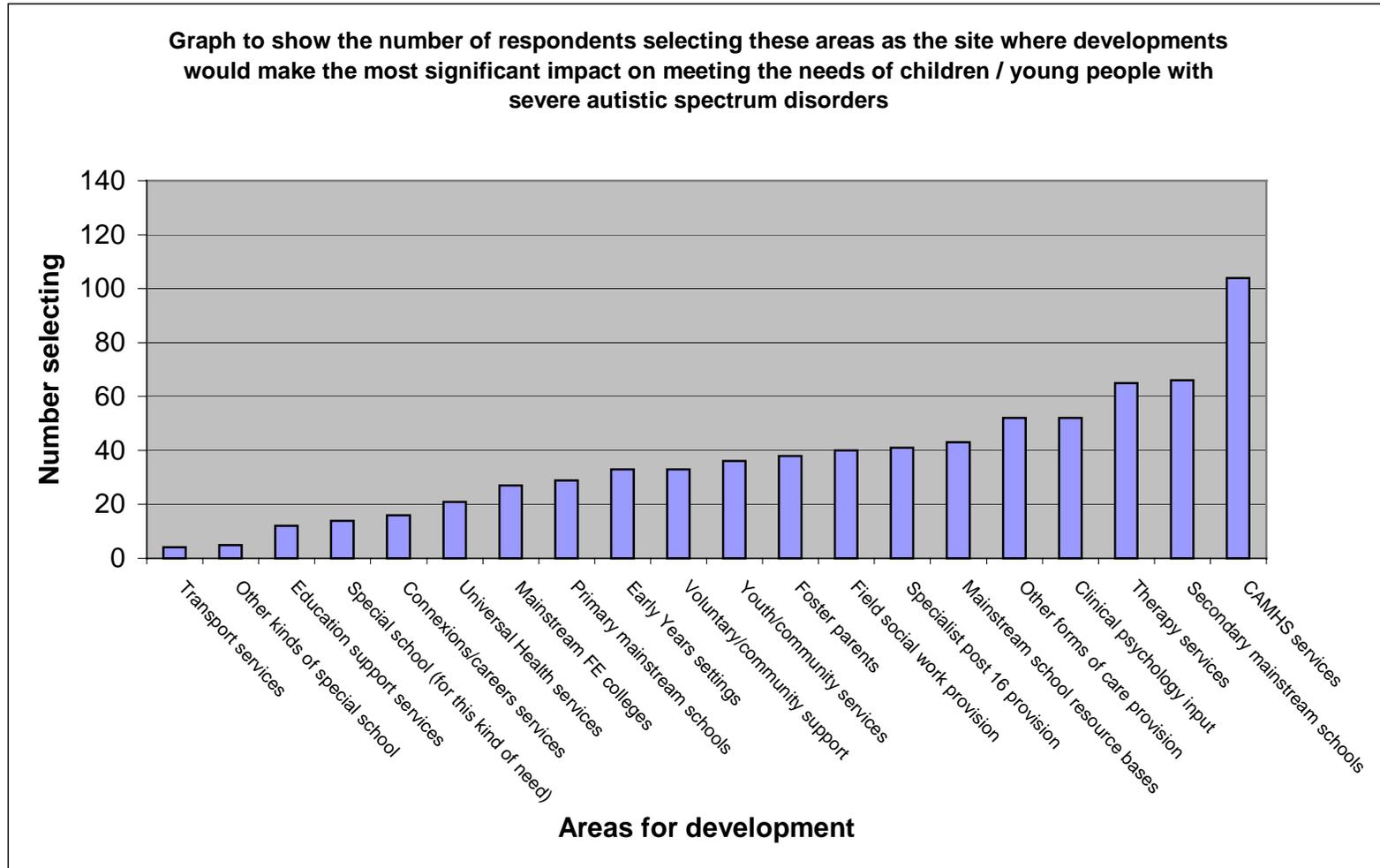
SEVERE BEHAVIOURAL, EMOTIONAL AND SOCIAL DIFFICULTIES:

3.36 The elements of provision listed in the questionnaire were generally regarded as important by all three agencies. The highest level of support was for 'appropriate school ethos, inclusion policies and support systems' (92% of respondents agreed these were important). The lowest level was for 'suitable arrangements for transport' (ticked by 68% of respondents).

Provision mostly in place

3.37 Average availability ratings ranged from 2.56 to 3.56 (see Graph 3.1 below), suggesting that the elements of provision required for this type of need were 'mostly available' (2) or 'available to some extent'(3). Availability ratings were slightly lower than for the other 2 types of need.

3.38 The elements rated highest, in terms of availability, were:

- suitable arrangements for transport
- clear and achievable steps for development/positive feedback
- positive and inclusive staff attitudes[25]
- support for school staff in developing positive/inclusive approaches

suggesting that these elements of provision are available mostly in some Authorities and to some extent in others.

Gaps in provision

3.39 The elements rated as least available were *suitable range of short break/respite opportunities*, *skilled/resilient foster placements*, *skilled support for mental health issues* and *training for parents/carers*. Given that these elements were generally ticked as important, they appear to be some of the biggest issues to address for children with this type of needs.

3.40 When responses for 'importance' and 'availability' were combined, the biggest gaps identified were similar to the above.

3.41 There was a high level of similarity in perspective between the three agencies for this type of need.

3.42 Generally, responses were similar across the regions. The main differences were in relation to *support for mental health issues* and the need for a range of *skilled/ resilient foster placements* (lower availability in North West, Merseyside, and NE London).

---

[25] This is encouraging in the light of concerns about negative attitudes towards challenging pupil behaviour.

Graph 3.1: Severe Behavioural, Emotional and Social Difficulties: Combined importance/availability ratings (elements of provision):
(score of 2 = important + mostly available; 3 = important + available to some extent; 4 = important but mostly unavailable; 5 = important but completely unavailable)
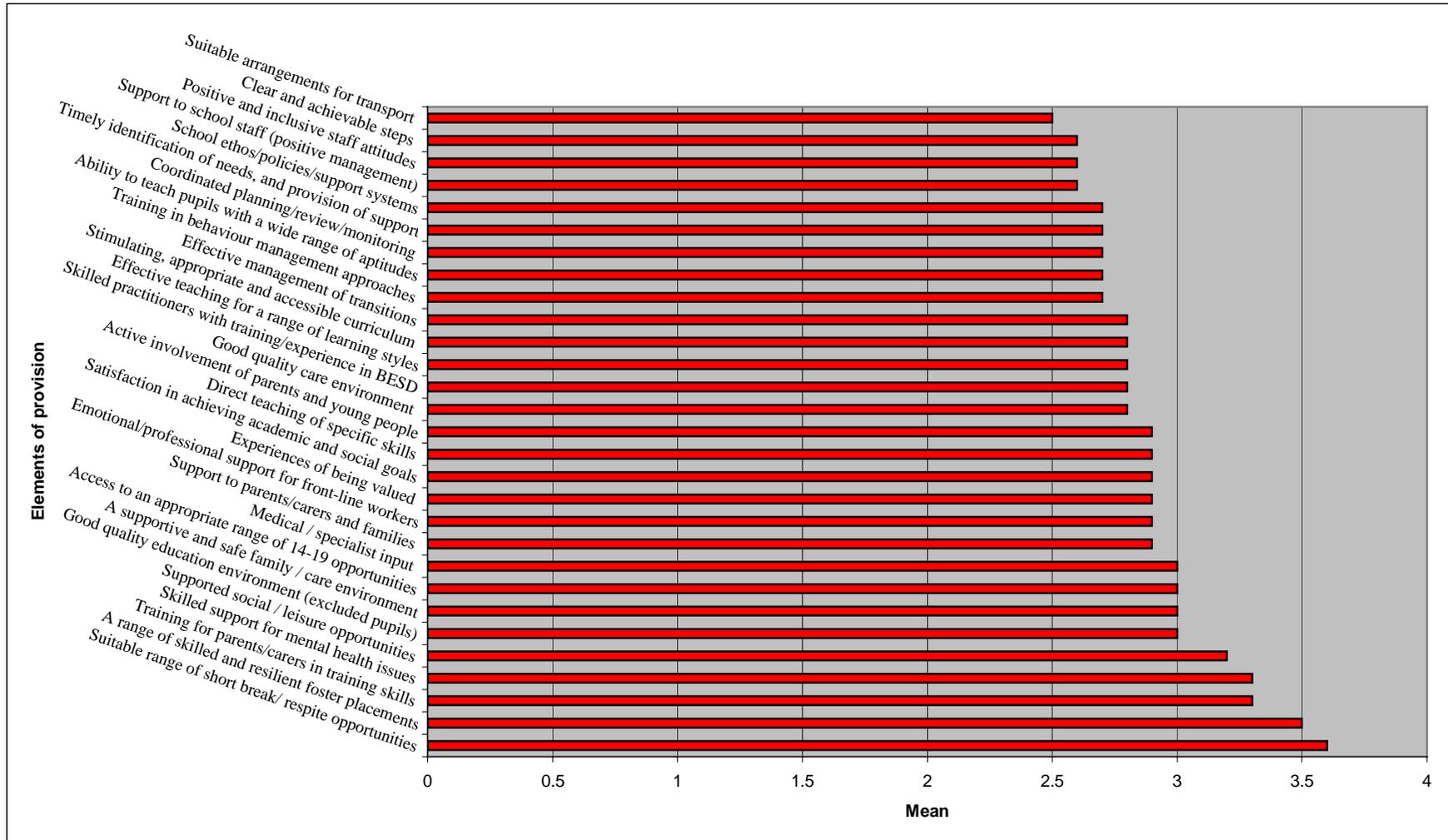
Graph 3.2: Severe Behavioural, Emotional and Social Difficulties: Priority gaps in provision (elements):

Graph showing the number of respondents selecting these elements as insufficient and capable of making the most significant difference in behavioural emotional and social difficulties

Y-axis: **Number selecting** (0 to 70)

X-axis: **Elements of provision**

Categories (left to right):
- Clear developmental steps & feedback
- Good quality care environment
- Suitable arrangements for transport
- Teaching for a range of learning styles
- Effective management of transitions
- Achieving academic and social goals
- Direct teaching of specific skills
- Medical / specialist input
- Ability to teach a range of pupils
- Appropriate school ethos
- Supportive & safe family / care
- Involvement of parents and youth
- Support for front-line workers
- Appropriate & accessible curriculum
- Positive and inclusive staff attitudes
- Experiences of being valued
- Training for professionals
- Good quality accommodation
- Co-ordinated planning and review
- Support to parents and families
- Support for school staffs
- Identification of needs, and support
- Supported social / leisure activities
- Range of 14-19 opportunities
- Skilled practitioners
- Training for parents in training skills
- Range of short break opportunities
- Support for mental health issues
- Range of skilled foster placements

3.43 Respondents were asked to identify the 3 elements from the questionnaire list (or others nominated by them), where they felt improvements/greater availability would make the most significant difference to meeting the needs of this group[26]. Graph 3.2 shows the profile of responses. The most significant gaps relate to the need for a *range of skilled foster placements* and *short break/respite opportunities* and *support for mental health issues*.

3.44 Agency priorities were broadly similar for this group. However, Education respondents tended to give greater emphasis than the other 2 agencies to the need for a 'more inclusive ethos in mainstream schools', with 'more effective teaching for diversity'.

Service/provision areas needing development

3.45 Respondents were asked to indicate the extent of development needed in a range of service/provision areas. For severe BESD, average ratings for different items were similar to the ASD picture, ranging from 2.92 to 4.14: (typically, an average amount (3) to some (4) - see graph 3.3). Areas where the highest ratings were given were: *secondary mainstream schools*, *foster-parents*, *CAMHS* and *other therapy services*. The lowest need for development was seen to be in the area of school age special school provision and mainstream FE[27].

3.46 There was a broad similarity between the perspectives of different agencies, though Education tended again to give lower ratings than Health and Social Services to the need for developments in a range of service/provision areas.

3.47 The regional patterns were very similar, though the South East placed greater emphasis than the other regions on the need for developments in *primary and secondary mainstream schools* and in *education support services* for this kind of need. Merseyside and Eastern Region gave slightly higher priority than the others to developments in *mainstream FE*.

3.48 Respondents were asked to nominate the three key service/provision areas where they thought developments would make the biggest difference in meeting the needs of this group. Graph 3.4 shows the profile of responses. *CAMHS* was by far the most frequently nominated area, with *secondary mainstream schools*, *mainstream resource bases* and *skilled/resilient foster parents* also receiving a high number of mentions.

---

[26] A small number of other elements were suggested, which added little to the main lists.
[27] A number of other developments were suggested, including improved community support and better vocational/pre-vocational provision, collaborative strategy, joint commissioning and pooled budgets.

Graph 3.3: **Severe Behavioural, Emotional and Social Difficulties: Need for development ratings (service/provision areas):**
(score of 2 = little development needed; 3 = average amount needed; 4 = some needed; 5 = much needed)
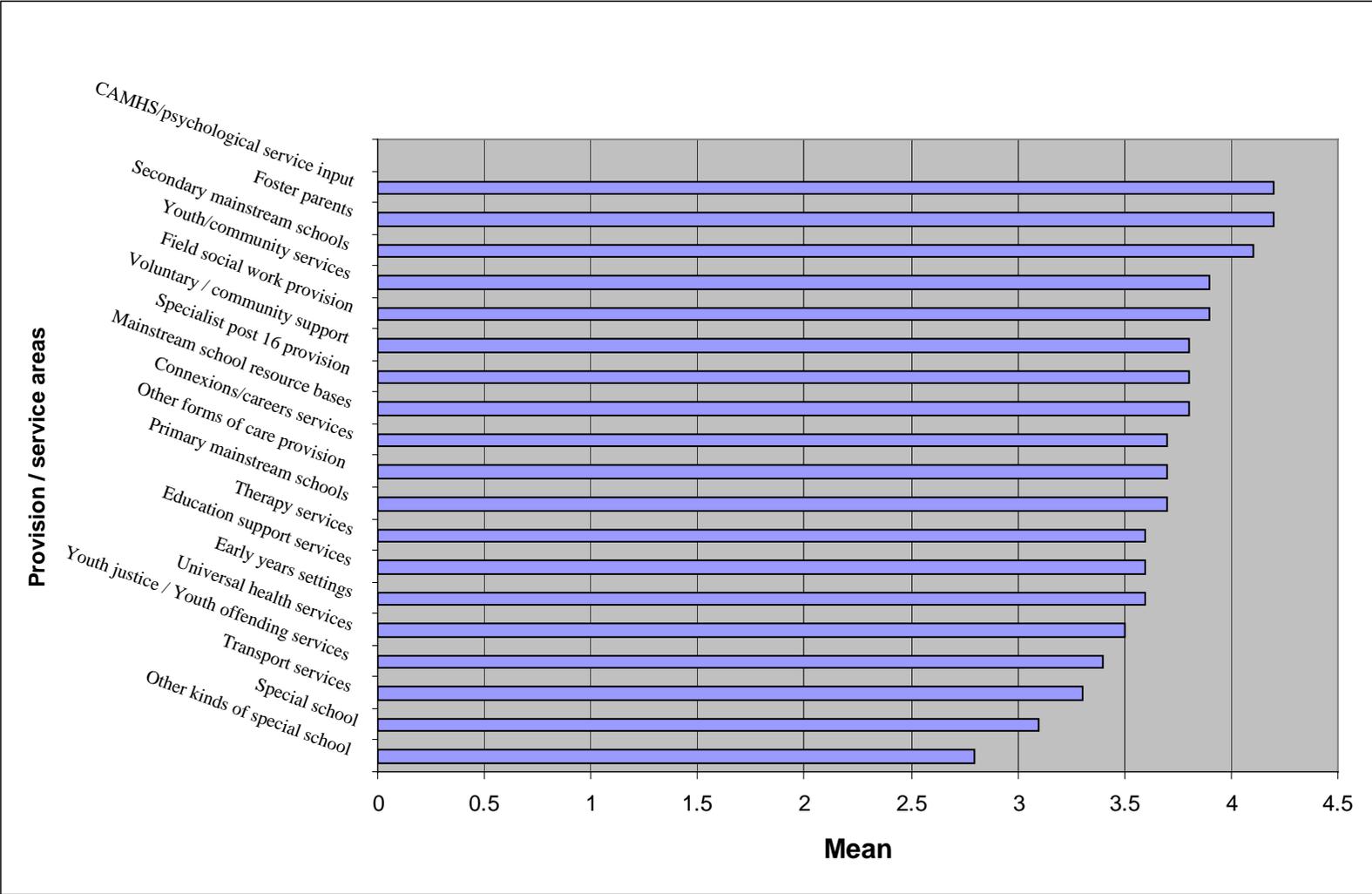
Graph 3.4: Behavioural, Emotional and Social Difficulties: Priority areas for development (services/provision)

Graph to show the number of respondents selecting these areas as the site where developments would make the most significant impact on meeting the needs of children/young people with severe behavioural, emotional and social difficulties

Number selecting

Areas for development
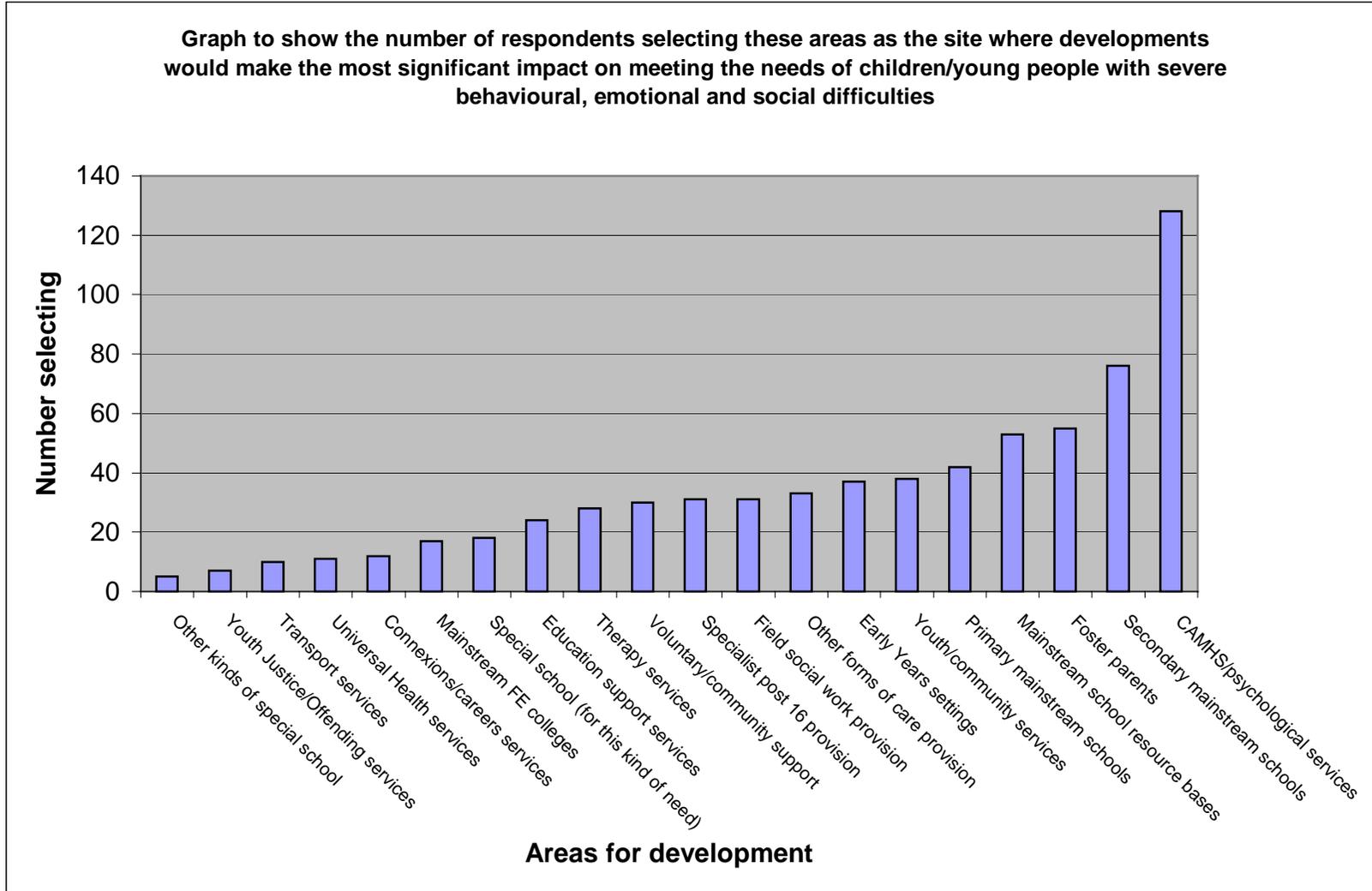
3.49 Education tended to give greater emphasis to developments in schools. Health and Education nominated a broader range of developments in residential care and fieldwork provision than Social Services (who emphasised fostering). Again, Social Services tended to mention developments in *youth service* provision and *voluntary/community support* more frequently than the other two agencies.

Confidence in capacity to meet needs

3.50 Confidence ratings were lower for this group. Responses suggested that agencies were less than 'moderately' (3) confident themselves (mean = 3.28) and they saw parents/carers as approaching a 'not very confident' (4) position (mean = 3.59). Agency comparisons again suggested that Education respondents were slightly more confident than their Health and Social Services counterparts

OTHER LOW INCIDENCE NEEDS:

3.51 The main additional group with low incidence needs, mentioned by respondents, was children with complex physical/medical needs. There was also some reference to those children who are at risk of self-harm, girls with significant BESD, and sexual perpetrators.

3.52 Developments needed were generally similar to those mentioned for the 3 main groups. For complex physical/medical needs, reference was made to the need for *better local respite with appropriate medical/health care support*, *strengthened links between community and acute health services*, and *improved resources and training*.

Other comments

3.53 A range of other comments was made, typically to elaborate on/exemplify responses. In addition, a small number of respondents highlighted the absence of questionnaire items relating to the 'safeguarding'/child protection agenda. For some young people with low incidence needs, this is reported to be a major issue, with services needing to be more alert to potential grounds for concern.

Summary of the main findings from the Questionnaire:

1) *Statutory agencies are generally more confident they are meeting the needs of children and young people with severe/profound sensory impairment than those of the other 2 main Low Incidence groups (ASD and BESD). They are least confident about their provision/services for those with severe/complex behavioural, emotional and social difficulties.*

2) *There is a reasonable level of consistency in view across the country, and between the different agencies.*

3) *For **sensory-impaired**, a number of the required elements of provision are seen to be in place, particularly in relation to specialist skills, equipment and resources. There is not a strong call for increased special school provision for this type of need.*

4) *The main gaps for this group relate to the need for more access to short break/respite provision and a better range of 14-19 opportunities. There is also a need for more coordinated planning and review, particularly at points of transition.*

5) *The priority service/provision areas needing development are CAMHS and other therapy services, post 16/FE provision and secondary mainstream schools.*

6) *For **ASD**, there appear to have been some improvements in early identification/ intervention, multi-disciplinary assessment and in the availability of ASD-specific teaching approaches. These are reported to be more generally in place. There is also better access to information.*

7) *The main gaps for this group are in the area of short break/respite provision, family keyworker support, support for mental health issues, and appropriate 14-19 opportunities. There is also a need for better access to social/leisure activities and for improved support with managing difficult behaviour.*

8) *The priority service/provision areas needing development relate to social care (fostering and other forms of care provision), CAMHS/therapy services, secondary mainstream school and post 16/FE provision. There is also a need for development in youth service and voluntary/community support capacity for young people with these kinds of difficulties.*

9) *For **BESD**, statutory agencies provide some evidence of more positive expectations, with support to school staff in developing more inclusive approaches. However, the provision required for the more severe end of the continuum is less available.*

10) *There are particular issues in the area of short break/respite and the availability of skilled/resilient foster-placements, training for parents/carers and skilled support for mental health issues.*

11) *The main areas identified for development relate to secondary mainstream schools, foster-parents and CAMHS services.*

12) *For complex **physical/medical needs**, there needs to be better local respite, with appropriate medical/health care support, stronger links between community/acute services and improved resources and training.*

4. FINDINGS FROM THE FOCUS GROUPS:

> *This section*
>
> - *Describes the purpose and broader constituency of the regional/subregional focus groups*
> - *Reports on the key themes and issues experienced by Local Authorities and other partners in addressing each of the main types of low incidence need*
> - *Identifies what Local Authorities and other partners are doing to address the main gaps in provision and services, with examples of positive practice*
> - *Reports the views of focus group participants on the potential shape and form of 'regional centres of expertise'*

4.1 The purpose of the focus groups was as follows:

    (i)   to share some of the key findings (national/regional) emerging from the questionnaire

    (ii)   to gather views from a broader range of local/regional stakeholders on significant gaps in provision for children with low incidence needs

    (iii)   to work towards a creative consensus on possible ways forward locally and regionally (including options for the role/contribution of regional centres of expertise).

4.2 Overall, 13 focus groups were organised, linked to the 9 new Government Office regions. Five subregional groups were held in London[28], in order that the ALCEO/London Challenge project agenda could also be addressed.

4.3 Nearly 400 people attended the focus groups (across all 13 events). Attendance rates for each of the regional/subregional focus groups are shown in Appendix 6(a). 91% of Local Authority areas were represented overall by the 3 main statutory agencies. However, fewer participants attended from Health and Social Services than from Education[29]. The main regional perspective was provided by the SENRP facilitators who were present at all the events. There was a good level of involvement from the Regional Development Workers (CAMHS).

4.4 The voluntary sector was quite well represented, particularly those organisations involved with sensory-impaired or with ASD (there was minimal representation with regard to BESD). Attendance by representatives from the independent/non-

---

[28] North Central, North East, South East, South West and West: these linked to the London SENRP subregional structure, which is based on London's strategic health authority areas. Arrangements were made through the subregional convenors (typically LEA officers working in the area).

[29] Significantly more had said they would be coming, but were unable to attend on the day.

maintained sector was less good than expected (except at the NW/Merseyside event). However, a number of voluntary organisation representatives were head teachers of non-maintained special schools.

4.5   Generally, the focus group participants endorsed the questionnaire findings and were able to elaborate on these and explain what they meant in practice for services and for children and families. Some additional priorities were discussed.

4.6   There was a reasonable level of commonality across the regions. In line with the questionnaire, there were some differences in service/agency priorities, and these needed to be borne in mind, in the light of the higher levels of representation at the focus groups from Education services.

4.7   Key themes emerging from focus group discussions are again reported for each of the three main types of need.

SEVERE SENSORY/MULTISENSORY IMPAIRMENTS:

Themes:

Inflexibility arising from category boundaries

4.8   There was general agreement that the main issues for this group occurred where children's difficulties were multiple (for example, where children had a range of other learning difficulties or physical/medical needs, as well as sensory issues). Multisensory impairments also presented greater challenges.

4.9   However, problems arose, not just because of the complexity of children's individual needs, but as a result of inflexibilities in school/service boundaries. Some educational establishments were less able or willing to make adjustments for those children who were less 'academically able' or who had other social or physical/medical issues.

4.10   The importance of multi-agency working was emphasised, with a need to extend the principles and practice of initiatives such as the Early Years Support Pilot Programme (ESPP) up the age scale.

Disability access issues

4.11   There was evidence that problems were still arising for some children with sensory impairments and their parents, because of disability access issues. These issues also affected those young people with a less complex pattern of difficulties.

Post 16 provision and child-adult transitions

4.12 Students with severe sensory/multisensory impairment encountered a number of difficulties at the 16-19 phase. For some, the mainstream 6th form option (even in schools with specialist resource bases for this kind of need) was not viable if the focus of learning was on traditional academic subjects. Some students who wanted to pursue a vocational route found that FE colleges were not always geared up for their particular learning requirements (adaptations, courses, personal support). This, and the lack of a peer group with similar impairments, was leading a number of students in the direction of specialist 16-19 provision, some way from home.

4.13 Funding restrictions also encouraged students to remain as long as possible within special school provision, so that college options could be pursued after 19. This meant that some students returned to their local community from specialist provision later than might be normally expected.

4.14 On the positive side, there was some evidence that LSCs (Learning & Skills Councils) were starting to look at more local options for specialist post 16 provision, and to find ways of reducing existing access barriers at college level.

4.15 A number of focus group participants considered that the move away to more specialist provision at post 16 was linked to the absence of clear progression pathways for young people with these kinds of needs. The 14+ planning process was seen as too short-term and not sufficiently person-centred. In some areas, there is insufficient involvement of key services such as Connexions, who are seen as giving greater priority to the more traditionally 'disaffected' population.

4.16 For those students with more complex/multiple difficulties, there are also significant discontinuities in provision planning at the point of transition to adulthood, and relevant information is not always properly shared at this stage.

Support for mental health issues

4.17 It was reported that young people with sensory impairments can experience a greater sense of isolation as they get older, particularly if their needs are not properly understood. This can lead to a number of emotional/mental health issues.

4.18 Counselling support is not readily available at this stage. CAMHS services were criticised for not being sufficiently accessible to young people with severe sensory impairments. This related partly to service shortfalls in a range of communication skills (BSL etc) and partly to inflexible service boundaries ('these children are not part of our normal client group – someone else must be able to deal with them').

4.19 Generally, focus group participants were not looking for extension of the traditional pattern of CAMHS clinic provision[30]. They wanted to see a much

---

[30] They regarded this as unrealistic and saw the 'clinic model' as rather ineffective.

broader range of contributions: for example, outreach workers who could co-work with other relevant agencies and specialists who could offer advice more indirectly to frontline services/schools.

4.20 Some participants were aware of specialist CAMHS Tier 4 provision (psychiatric units) that linked specifically to young people with severe sensory impairments. A number argued that this capacity should be brought closer to home, with local mental health services strengthened and more differentiated in order to meet individual needs better, more locally.

4.21 Support for mental health issues needed to be looked at more broadly: it needed to include greater opportunities for social/leisure activities, where staff were skilled and experienced in working with young people with these kinds of needs, and where there were better opportunities for young people to meet same-aged peers with similar disabilities.

4.22 There were also broader aspirations for the contribution of other therapy services (speech and language, occupational, physio), which needed to develop their role, so that local provision was strengthened[31].

Short break/respite issues

4.23 A number of barriers were reported in access to care support for children with severe sensory/multisensory impairments and their families. These related partly to the thresholds that tend to be operated by some Social Services Disability Teams (priority being given to those with significant learning disabilities). But there were also issues about the levels of skill and experience available for these kinds of children within the range of normal care provision (shared care/short-term fostering and residential units).

4.24 It was reported that parents often pushed for the residential school option when they had been unable to obtain the support they needed for 'care' provision. For instance, in tribunal hearings, they would sometimes put an emphasis on the child's need for specialised education in order to 'make the case' for provision that was lacking from other services.

4.25 While acknowledging the need for more specialised capacity and a wider range of options at local level, Social Services representatives felt that the local 'package' needed to be much broader, including access to better extended day care provision and more suitable/accessible recreational opportunities.

Workforce issues

---

[31] Therapy issues can be a significant factor in parents requesting out of Authority provision. Participants were conscious of capacity, recruitment and retention issues, but felt that local working links between therapy services and other professionals could be further developed.

4.26 A number of participants raised concerns about the recruitment and retention of specialist staff. It was reported that fewer teachers were putting themselves forward for specialist training (HI, VI and multisensory), and the age profile of existing specialists is getting older. There were also concerns about the loss of specialist knowledge and experience at the teaching assistant level, particularly in the context of greater delegation of statemented support to individual schools and the wider Workforce Remodelling agenda.

4.27 There is also more pressure on specialist teaching services for the deaf, as a result of increased demands arising from neonatal screening.

4.28 There was concern about the variation in availability of specialist skills (eg numbers of specialist HI/VI teachers) across different parts of the country, and the isolation of some staff working in smaller Authority areas.

4.29 While participants recognised the need for specialist training and experience for those working with children with these kinds of needs and their families, a number argued that traditional patterns of service organisation might not be the best way of addressing the problems. The new Children's Services and the national Children's Workforce reforms allowed local authorities and health services to review the range of skills that were needed and ensure that these were available across all relevant services/provision.

4.30 It was argued that there needed to be better and more coordinated local capacity for working with children with the most severe/complex needs, which implied greater ability within *universal* providers (mainstream schools/FE, universal services) to meet the needs of most young people with sensory impairment, and more flexible responses from existing specialists.

Ways in which gaps are being addressed (and examples of positive practice[32]):

Post 16/transitions

4.31 In the area of post 16 provision, reference was made to individual mainstream FE colleges that were providing more targeted arrangements for severely sensory-impaired students. There is also evidence of growing specialism within the mainstream FE sector. For example, in the North East, the LSC is setting up 2 regional 'hubs' (with RNIB) in Middlesbrough and Newcastle, which will offer more specialised arrangements for some students with visual impairments, and provide support and advice to other colleges in their locality.

---

[32] These examples were provided during the focus group discussions and have not been validated specifically. The vignettes describe practice that was followed up in more details; for these, there is stronger evidence of positive outcomes, for example, through reports of improved parental satisfaction, reduced reliance on out of Authority provision, and better access to relevant services.

4.32 The North East has also developed a Sensory Support Partnership in order to support school to FE transition. This is currently funded as a charity.

4.33 The LSC in South London has developed a 'Learning Choices' project to improve transitions to FE and work-based learning, with more specialised guidance and a wider range of choices for severely sensory-impaired students. In the South East/ South Central region, deaf mentors have been used to help young HI/deaf people plan more proactively for their future.

RNIB/FE College Partnerships

Following some pilot work in Liverpool, the RNIB is working to identify a small number of sector colleges in each government region that would like to specialise in direct provision and support for blind and partially sighted learners. The intention is to establish a joint, specialist visual impairment support centre and service, in partnership with each of these carefully selected and designated colleges. This would offer direct teaching to discrete groups of blind and partially sighted learners where it is required as well as providing intensive support for blind and partially sighted learners and their tutors on mainstream programmes. It may also include some residential provision. Each of these specialist centres will then form the "hub" of an "outreach" service delivering less intensive support for visually impaired learners and their tutors at other providers in the sub-region.

The College Partnership programme acknowledges the fact that visual impairment is a low incidence disability and each individual college may not be able to afford and provide the expertise and specialism to meet the needs of all visually impaired learners.

RNIB has been working closely with the Learning + Skills Council in formulating the College Partnership programme at both the national and local level. Development funding for each College Partnership comes from LSC through its Local Intervention and Development funding (LID). The expectation is that LSC will fund a significant part of the development over 3 years and the partnership college will adjust its additional learning support funding to take account of the increased numbers of visually impaired learners. This will allow the initiative to be maintained and generalised.

Partnerships are currently being developed in Newcastle and Middlesbrough.

Contact: Mark Braithwaite: RNIB

> *Points of Interest*
>
> - *Regional planning, co-ordination and provision of specialist services, with commensurate economies of scale*
> - *Partnership working across voluntary sector and public sector agencies*
> - *Specialist support provided directly to those with a severe level of disability; regional expertise also accessed cost-effectively to those on the VI continuum*
> - *Small amount of potential residential access is feasible if deemed to be required*

4.34 A number of areas have developed 'multi-agency transition teams' to support the move to post 16, and from child to adult services. In Wolverhampton, transition packs are now available specifically for sensory-impaired students, and the South West has developed multi-agency 'transition protocols'.

Transition Packs for students with sensory impairment: Wolverhampton

The information pack was devised by the Wolverhampton Sensory Inclusion Service to meet the needs of young people moving from children's services into adult services. The pack is given to all deaf students in Year 9 by their specialist support teacher. It includes information about their hearing loss and how it affects them. It also includes information about other agencies and the local hearing services they might need and how to access them.

The Sensory Inclusion Service holds a conference for deaf students to meet one another, and invites speakers from the different agencies (Connexions, Social Services, Audiology Services). The highlight of the event is an input from a young adult deaf person who talks about issues he/she has faced. The conferences have been very successful and will include VI children this year. The National Deaf Children's Society has used Wolverhampton LEA as a model of good practice in their recently published 'Quality Standards for Transition'.

Contact: Jean Haigh: SEN Officer, Wolverhampton

Points of Interest

- *Meaningful support for young deaf people making the transition from children's to adult services*
- *Information provided directly to young people to enable them to make sense of, and to access appropriate adult services*
- *Contact and connection with disabled peer group*
- *Potential to extend this successful model into VI transition*

Extending staff/family skills

4.35 A range of training initiatives were reported, at local and regional/subregional level. Examples were given of BSL communication being more routinely available, for example in Tower Hamlets[33] Children's Centres and in Wigan's Social Services reception areas.

4.36 Oxfordshire runs a partnership project, involving parents (through the local Deaf Children's Society), Social Care, Health and Education, aimed at teaching signed communication approaches to a range of professionals and family members.

---

[33] Tower Hamlets is reported to have a high incidence of deaf/HI children from Bangladeshi families.

Extended care and leisure opportunities

4.37   There are examples, particularly in urban areas, of special schools starting to provide a wider range of services[34]. These include both social/leisure opportunities and targeted respite/family support arrangements. In London, Harrow is working with the RNIB to develop greater capacity for pupils with severe learning difficulties and visual impairment within its SLD special school. This will include a small residential provision.

4.38   In Tower Hamlets, youth groups have been set up after school, using deaf interpreters to help improve access and participation in leisure activities.

4.39   In the South West region, RNIB is organising a range of leisure options for pupils with visual impairments together with non-disabled peers.

Links with CAMHS/support for mental health issues

4.40   There were some good examples of improved service links. In the West Midlands, a link has been established between the deaf community and CAMHS (through a Health-funded Deaf Support Worker[35]) in order to improve service access when young people with HI are referred. A project was reported in Yorkshire, where CAMHS and deaf service are working together to develop family support.

Multisensory impairments

4.41   A project has been developed in Leeds, focusing on children with multisensory impairments in the Early Years.

4.42   In the West Midlands, a small number of MSI 'intervenors' have been appointed to assist in the communication between children with these kinds of needs and the 'outside world'.

4.43   Generally, participants spoke positively of the inputs from SENSE (charity for MSI), which had worked to support and improve the skills and expertise of local practitioners.

Joint reviews of provision and commissioning

4.44   A number of Authority areas have engaged in reviewing their provision and services for severe sensory/multisensory impairments and a range of other disabilities. In some cases, this has led to shared service developments. In others, smaller Authorities have joined together to 'jointly commission' provision. Some

---

[34] More difficult in rural areas where children may travel from a longer distance
[35] based in Dudley

still share specialist support services[36]. Others 'share' special school provision (as in the North West where a number of Authorities in the Greater Manchester area use a primary deaf/HI provision in Bolton).

The contribution of RCEs (regional centres of expertise):

4.45 Participants generally did not favour the notion of 'regional provision' – which children attended full-time on a day/residential basis. This is more viable (and already happens) at a subregional level, particularly where small Authorities share provision, as mentioned above. Some participants felt that a regional provision (visited by children/families) might be useful for providing more specific inputs (eg specialised assessments; specific therapy/advice; residential leisure/short break care support). However, the main function people needed from a regional centre was 'support for building local capacity'[37].

4.46 A regional centre might help in providing specialist equipment and advice to support local interventions. It might be a focus for training. It might carry out research and development, to pilot and evaluate new methods of working.

4.47 At a more strategic level, it might help in regional/subregional mapping of skills, gaps and development needs, in planning developments in provision and commissioning new initiatives to address unmet needs. It might play some role in developing standards and monitoring quality.

4.48 Some participants argued for a more 'virtual' model, with looser networks forming around existing areas of strength and interests. This model did not necessarily involve 'one place' where professionals or children/families would go.

SEVERE AUTISTIC SPECTRUM DISORDERS:

Themes:

At risk groups

4.49 It was recognised that the range of children defined as ASD had widened and that there was a need to focus on those groups most at risk. The two main groups where there were significant issues were (a) those children with severe ASD who also had significant learning disabilities/challenging behaviour and (b) those children identified as 'higher functioning' (who might be able to deal with the academic demands of a mainstream curriculum but might experience a number of social communication issues). The concern around secondary mainstream

---

[36] For example, in the old Berkshire, Humberside, and Avon authority areas, these were retained following local government reorganization.

[37] This was a common theme across all LI needs types.

provision related to the latter, where there are significant risks of social isolation and school exclusion.

Inter-professional tensions/need for joint planning

4.50 There is currently a wide range of professional attitudes and beliefs around ASD, which can hamper effective work with children and their families, particularly in the most difficult and challenging cases, where there is a need for a consistent approach. We should not be relying, as one group put it, on 'individual clinicians' whims'.

4.51 Parents/carers are also drawn to a wide range of theories and intervention approaches, which can lead to a divergence of opinions.

4.52 In these circumstances, joint arrangements for identification, planning and review are vital.

4.53 This is particularly important in the area of identification/diagnosis, where centralising capacity too narrowly can lead to long waits for anxious parents, sometimes with little support and intervention in the meantime.

4.54 Concerns were expressed about the pressure on professionals to diagnose in order that children and families could access the services they needed, and the lack of follow-up support in some areas after diagnosis.

4.55 A number of participants reported the benefits of multi-agency training, where all relevant agencies were familiar with and using the same approaches, both at a broader level and in relation to individual children.

4.56 Issues raised in relation to CAMHS were generally about boundaries, with some children falling through the gap between mental health and learning disability services[38]. There were barriers to accessing other therapy services in some areas, as a result of their emphasis on shorter-term outcomes and discharge.

4.57 Fragmentation in professional views and local uncertainties about roles and responsibilities were also cited as issues that might be raised in SEN Tribunals, when parents/carers were looking for out of Authority provision.

Family support and respite issues

4.58 Participants reported that these were the biggest issues needing to be addressed. They pointed to the need for early intervention and support for families once a

---

[38] In some areas, CAMHS clinics do not get involved with ASD children; in others, they are central to the diagnosis and decision-making process.

diagnosis is made[39]. However, without ongoing support over time, there is an increased likelihood of family breakdown, especially with children whose behaviour is particularly challenging. This typically resulted to residential school provision, which, almost inevitably, led to continuing residential placement in adulthood.

4.59   Some of the problems related to an insufficiently differentiated range of respite options. Parents and young people with ASD themselves tended to reject residential units that more typically supported children with significant learning disabilities (and where staff appeared to be inexperienced in ASD issues). There were insufficient numbers of foster-parents/shared care families with ASD experience, and these were not regularly available. Children with ASD did not generally find it easy being away from their accustomed routines. So, separation from family and home could be particularly troublesome. Children needed different types of provision at different ages and stages.

4.60   A number of participants pointed out that, in planning suitable respite provision, account needed to be taken of both parents/carers' and children's needs, which could sometimes be in conflict.

4.61   Again, Social Services representatives pointed to the broader issues in children's lives, the risks of social isolation for them and their families, and the importance of a wide range of supports, including better recreational/extended day opportunities.

4.62   There were differing views about the value and benefits of the Government's 'direct payments' scheme. For some, this was providing a wider range of options, sometimes in settings that were more familiar and less stressful for the children and their families. For others, it was making it more complex to plan and deliver an effective range of services at local level.

Transition issues: post 16 and beyond

4.63   A number of the issues raised with regard to children with severe sensory/ multisensory impairments were repeated in relation to ASD. Again, there are difficulties at transition points, particularly as young people leave school and move on to further education and adult services. At this point, there can be significant discontinuities in health/social care provision and in approaches to teaching and learning.

4.64   There was also reported to be a lack of longer-term planning and insufficient involvement of relevant services in helping young people and their parents/carers identify suitable pathways for the future. Families needed continuing support,

---

[39] At worst, there can be a strong discrepancy between the time and effort given to diagnosis and the extent of support available once the diagnosis has been made.

which should not be interrupted just because of differences in organisational systems and priorities.

4.65 Lack of funding for transport to post 16 provision could also be an issue for some families.

Building local capacity

4.66 Generally, participants emphasised the need to develop more coherent local packages for children with severe ASD. Specialist techniques and interventions were insufficient in themselves. There was a need for a broader level of support across all relevant ECM areas.

4.67 With more children being identified and diagnosed, it was important to keep a focus on the most complex/challenging end of the spectrum. This implied improvements in some aspects of universal provision (eg ordinary secondary mainstream schools) to help ensure that specialist/additional resources did not drift away from their priority target.

Ways in which gaps are being addressed (and examples of positive practice):

Improving local capacity

4.68 In a number of Authority areas, local special schools are being developed and extended to provide for children with more complex needs. In Southend (St Christophers), Sheffield (Bents Green), Coventry (Corley Centre) and Cornwall (Nine Maidens), this has led to significant reductions in the need for out of Authority placements. Some special schools are extending their services to include outreach and respite care support. In Barking & Dagenham, Trinity special school has developed a 'Living and Learning Centre' for young people with very complex ASD and challenging behaviour, which is able to provide for a number who have been excluded from the residential special school sector.

4.69 In some areas (eg Nottinghamshire), special schools have developed their own ASD network to help develop good practice.

4.70 Within the mainstream sector, Sandwell's Complex Communication Disorders/ ASD team have been working in one secondary school, focusing on environmental adaptations, curriculum differentiation, training and social opportunities. It is envisaged that the provision made for students with ASD at this school will become a model for provision in two further identified high schools within the Authority.

TRINITY SCHOOL LIVING AND LEARNING CENTRE

Trinity is a special school in the London Borough of Barking and Dagenham. It was created following the amalgamation of 3 special schools for children with learning and physical/medical difficulties. It is now a large all-age generic special school that provides for a wide range of needs, including about 70 pupils with Autistic Spectrum Disorders.

The Living and Learning Centre is a relatively new development, designed to meet the needs of 14-19 students with the most complex and challenging behavioural difficulties. The first group of students admitted included a number who had missed education for extended periods or were receiving very limited amounts of provision because of the behavioural challenges they presented. The Centre has been an integral part of the Local Authority's plan to enhance local provision and reduce the need to place children residentially away from their home and neighbourhood community.

The LLC is open 48 weeks of the year and can offer an extended school day. Programmes are entirely individualised and are tailored to the needs of students and their families e.g. poor sleepers and late risers can start their day later and finish later. The LLC has its own transport and driver, which facilitates this level of flexibility.

Extensive use is made of the TEACCH approach. All staff have received training, the majority in North Carolina, and ongoing professional development and impetus is maintained through support each term from one of their consultants.

A specialist Educational Psychology post for autism was created shortly after the provision opened and weekly support is provided with the focus on further developing the skills of staff in observing, assessing and problem solving around behavioural difficulties. Social services have been closely involved with all the students and their families in respect of transition to adult life as well as seeking to provide effective support for families. There are ongoing issues in respect of respite that is capable of meeting the needs of this challenging group and provision of services post 19 but these are being progressed.

Programmes are geared to the needs of individual students, but are generally focused on developing communication and preparing for life after school. Care is taken to adopt structures and approaches to support self-management of behaviour that can be generalised to other settings and the home.

The provision is managed strategically by a senior manager within the school and has a deputy manager who deals with day to day running and organisation. Each student has an allocated key worker who delivers the greater part of the student's programme and there are three Learning Support Staff who facilitate community access and links to a broader range of activities.

Contact: Helena Hardie, HT, Trinity School

> *Points of Interest*
> - Reduction in reliance on out-of-authority placements due to investment by Local Authority in new provision, following special school re-structuring
> - Specialist Educational Psychology input supports on-going staff development in student behaviour support and self-management
> - Highly individual, tailor made support for young people with ASD and challenging behaviour
> - Extended services developed through multi-agency resourcing

4.71 There are examples of other local service providers developing more flexible working practices to help meet children's needs. In Harrow, the Speech and Language Therapy Service now concentrates its direct work on children with more complex and long-term needs, having demonstrated that it works most effectively with other groups through indirect work with teachers and teaching assistants in schools.

4.72 There is evidence in some Authorities of CAMHS seeking to provide more advisory support to front-line workers, for example through regular visits to special schools.

Developments in family support/short break care provision

4.73 In a number of Authorities, improved arrangements have been made for support to children and families in their homes. Blackpool and North Tyneside have appointed teams of family support workers. East Dorset and Cornwall have developed multi-agency intensive support teams, focusing on issues around challenging behaviour.

4.74 Northamptonshire has developed a broad range of family support services, specifically in relation to children with ASD. These have proved very successful and have done much to reduce the need for out of Authority residential placements.

4.75 The Tower Centre in Tower Hamlets also provides a range of services, including social/leisure/extended day options for young people up to and beyond 16. Family support services include care within the home, to allow parents to have a break while the child remains within familiar surroundings. There is evidence that the flexibility of options and close working relationships with the children and families has significantly delayed entry into the residential sector. A similar range of services is provided by Newham ('Real Life Parenting'), using voluntary sector/Children's Fund support and by Wakefield Children with Disabilities team.

4.76 NORSACA (Nottinghamshire Autistic Society) is providing targeted support for siblings.

Leisure

4.77 There are a number of positive leisure developments within the voluntary sector. For example, 'Somerset Supporters' provide sessional leisure support as well as babysitting services to ASD children.

4.78 Bournemouth Council has appointed a joint leisure development officer to help create improved leisure access for children with a range of needs (including severe ASD).

Northamptonshire family support services for children and young people with ASD

Northamptonshire Local Authority has a well-established range of provision for family and short/long term residential support for children and young people with Autistic Spectrum Disorder. The provision began in 1993, in response to Local Authority and families concerns regarding children with ASD being placed out of the county, frequently in residential schools. All of these services are based upon the use of the TEACCH approach, an autism-specific model of service delivery which is also used in educational provision for children with ASD in the county: this enables consistency and continuity to be provided for these children between home, school and short breaks settings.

Any child/family being considered for a service from the Autism Family Support Team or accessing the residential units must meet the Disabled Children's Service's eligibility criteria, and must have been assessed as requiring such a service.

The authority has three strands of support for families and for young people themselves:

1. A **Family Support Team**, working outside of '9 to 5' hours to support families, through a team of 5 staff. The team's role is to work with the parents of children with autistic spectrum disorders (ASD) to empower them to introduce structure, predictability and consistency into the child's home and community, and to enable parents and other family members to develop a greater understanding of the child with ASD's behaviour. Work is usually undertaken in the family home and community.

2. **Short breaks:** The purpose of this time is to provide both the parent and the child with a 'short break'. In the main, short breaks do not exceed more than 3 or 4 days in any one stay.

3. **Long term residential support:** There is a clear expectation that other, less intrusive services to support children (such as sessional support, Family Link or residential short-term breaks) will have been considered and assessed as inappropriate to meet the child/family's level of need for support before a referral to long term support.

Since the introduction of this support, out of authority placements have reduced and remained consistent; in the current financial year, social care fund only 3 out of authority placements for children with ASD.

Contact: David Preece, Team Manager, Services for Children with Autism, Northamptonshire Children and Young People's Service. E-mail: dpreece@northamptonshire.gov.uk

---

Points of Interest

- Response of Local Authority to parental and family needs across education/social care/leisure needs of this specific group.
- While TEACCH is the selected approach in this Local Authority, the significant feature in the continuity of support to children and young people with ASD is the consistency of the service delivery model.
- Significant reduction in use of out of authority residential placements for ASD pupils.

4.79 A number of special schools (independent/non-maintained and maintained) are trying to create more extended day and leisure opportunities. This appears to work well in urban areas. However, where home-school distances are greater (for example, in rural shire counties), there can be access and transport issues.

14-19/transitions

4.80 Few examples were given of positive practice in FE colleges for the more severe end of ASD[40], and there is national evidence from the literature that access for this group has traditionally been more restricted. However, Newham have linked with the National Autistic Society to appoint 14-19 support workers and are developing 'multi-media profiles' to help provide accessible assessment information to post 16 providers. Robert Ogden, a National Autistic Society school in Rotherham, is working to develop personalised alternatives for young people with severe and challenging ASD at Key Stage 4 who have been excluded from other forms of provision.

Multi-agency training

4.81 A number of participants reported that this had been very successful in the ASD area and helped ensure greater consistency in practice between the range of relevant agencies, parents/carers and schools. Dorset, Bournemouth and Poole have collaborated to extend this into an accredited training programme.

Increased partnership working

4.82 In a number of Authorities, steps have been taken by agencies to work more closely together, involving parent representatives and the voluntary sector. There were positive examples of joint initiatives. For example, Nottinghamshire Council has collaborated with its local independent/non-maintained special school (Sutherland House) to develop a joint early intervention service ('ECAP').

4.83 A number of Authorities have set up Autism Working Groups to help develop good practice across all sectors.

4.84 Bournemouth, Dorset and Poole have collaborated on a 'Pan-Dorset' review of services for children with disabilities, which was led significantly by parents/ carers. This has led to the development of an ASD strategy/focus group, which has resulted in a joint diagnostic tool, sharing of expertise and a range of joint training opportunities. Bromley have an Autism Standing Forum that has a similarly high level of parental representation and reports directly to the Children and Young People Unit strategic development team.

---

[40] Some special school initiatives are reported, which endeavour to access some elements of FE college courses

Pan-Dorset Multi-agency Review of Services for Children with a Disability

Following local government reorganization, Bournemouth, Dorset and Poole have continued to work together to develop services and provision for children with SEN. This subregional initiative started in 2002 and anticipated the national move towards more integrated service working.

The aims were to conduct a comprehensive review of the needs of disabled children and young people; to produce a five-year multi-agency improvement plan; and to implement the initial phase. A Project Manager was recruited and partner agencies were engaged at Chief Executive level.

The review was carried out with the active involvement of young people, parents and voluntary sector organizations. The final report outlined ten key principles around inclusion, prevention & early identification/intervention, single integrated assessment process, services focused on need with local delivery, families empowered to have maximum control of care, person-centred well-coordinated transition to adult services, involvement of parents and young people in strategic planning, service planning and individual planning. The initial priorities related to participation of young people, service coordination, behaviour coordination, early support, access to out of school activities and residential short breaks.

In April 2005, two joint commissioning groups were established (for East and West Dorset), involving key senior postholders representing Education and Social Care services from each of the three authorities, plus senior staff of the relevant Health Trusts. These have generated developments in relation to early years/early intervention; integrated services for ASD; development of a short-breaks service; and participation of young people.

A recent progress report concluded that investment over two years by all the partner agencies in the review had hugely increased the profile of services for C&YP with disabilities and had successfully engaged parents and young people in the process of service improvement.

Contact: Mike Dishington (Bournemouth) or Judy Pritchard (Dorset)

Points of Interest

- *Sub-regional planning and commissioning of services for children with SEN*
- *Key principles of service planning and delivery informed by young people themselves, their families and voluntary sector organizations in the area*
- *Successful engagement of young people and their parents in the process of service improvement*
- *Integrated service approach since 2002*

4.85   The National Autistic Society is taking active steps to support local developments in provision. It has made clear in its education strategy that it wants its own schools to focus more substantially on children with the most complex needs, working with more local services to cater more effectively for the 'majority'.

4.86   Finally, collaborative steps have taken between individual Authorities under the aegis of the West Midlands and London SEN Regional Partnership initiatives. For example, four Local Authorities in the London North Central subregion have worked together to develop a protocol/criteria for agreeing funding and clear entry/exit guidelines for Lovaas support[41].

The contribution of RCEs (regional centres of expertise):

4.87   There was considerable similarity in views expressed about the nature and role of regional centres as with the area of severe sensory/multisensory impairment. Again the emphasis was on supporting the development of local capacity. However, there was greater willingness to consider some form of subregional provision for children with more complex needs, to avoid having to use residential placements a long way from home. Joint commissioning across individual Authorities might be necessary for this to work effectively.

4.88   Other roles suggested included the development of some form of regional good practice network, as already happens in the West Midlands, through links between individual Authorities, the SENRP and Birmingham University. There could also be a form of regional training brokerage, to ensure greater consistency in the use of training providers and intervention approaches.

4.89   A regional centre might also be able to monitor local practice and benchmark, to ensure consistently high expectations, and encourage extension of good practice in the development of relevant services.

4.90   It was also argued that a national centre might be needed, with a research and evaluation function, so that practice could become more evidence-based and rely less heavily on stereotypes and individual preference.

SEVERE BEHAVIOURAL, EMOTIONAL AND SOCIAL DIFFICULTIES:

Themes:

Weight of demand

4.91   Participants reported that the level of demand for support for individual children and young people with behavioural, emotional and social difficulties was very

---

[41] Intensive home-based intervention (see literature review for further details)

high. This tended to lead to reactive responses by the range of agencies. There was a danger that those most at risk could be missed.

4.92 It was argued that improvements were needed in universal provision (for example, in mainstream school capacity and community resources) and in targeted early intervention (SureStart/Children's Centres etc), in order that higher level/tier responses could become more discriminating.

4.93 At present, some young people with very challenging needs, who are 'high risk' to themselves (and to others), get very little provision, whereas others may end up in longer-term residential placements (even when these are no longer needed). There is a need for a more tiered and systematic approach to provision.

Need for shared values/a common agenda

4.94 Disagreements about the best approaches with young people with severe BESD are not limited to professional beliefs. In this area, there are also differences in values, aims and goals, which get in the way of collaborative working between agencies, and between agencies and schools/local communities.

4.95 One key aspiration was that services shared ownership in relation to the most challenging young people, and did not 'pass the buck'. This would entail re-prioritising or 're-commissioning' for some existing services. Reference was made to the value of keyworkers who stuck with difficult young people 'through thick and thin'.

Need for greater coordination of services

4.96 Coordination of inputs is not just an issue at the individual child/family level. Participants were concerned about the level of fragmentation across both national and local initiatives and the short-term nature of funding to support greater social inclusion. There was concern that initiatives were too often introduced on a 'kneejerk' basis, without clear consideration of how they might link with existing strategies.

4.97 It was felt that more coordinated and longer-term responses needed to be established at a local level, with joint funding on an 'invest to save' basis, so that agencies could work together to 're-engineer' provision so that it was less reactive and more effective. However, a number of participants reported that it was difficult to obtain funding for proactive investment, when budgets were already under pressure as a consequence of the continuing need to make high cost (reactive) placements.

4.98 Better use could be made of the voluntary/youth/community sector, which could make a more significant contribution to supporting young people with severe and complex BESD.

Groups where there are particular issues

4.99 Participants highlighted particular groups where there are issues in making suitable provision. These include young people who have been traumatised, those with acting out/violent behaviour, girls (who have historically been a 'challenging minority'), and those with significant emotional/mental health needs, who may withdraw/not attend and whose needs can go unnoticed.

4.100 Generally, however, 'low incidence' BESD was seen as a matter of extremes, including circumstances where there were breakdowns in a number of areas at the same time (family, school and community).

Developments in care provision

4.101 The emphasis with this group of young people needed to be on building greater 'community and family resilience'. Social/leisure opportunities and extended day care need to be more accessible. Children with severe BESD are often the first to be excluded from organised activities and currently present significant challenges to out of school clubs/provision. This places an even greater burden on families who may already be at risk of breakdown.

4.102 Stability in these areas is also needed to support foster placements. Foster parents need to be particularly resilient and skilled. In a number of areas, these kinds of people can be difficult to recruit and retain, particularly where there is a 'mixed economy' (for example, where there are a significant number of private fostering agencies needing to recruit to provide care for children coming in from other areas (such as London)).

4.103 Specialist foster-parents need to be retained and supported, and they need a higher level of remuneration, on an ongoing basis, not just 'as and when'. They need prompt and accessible training and support from all relevant agencies.

Support for mental health issues/CAMHS

4.104 CAMHS was a significant issue raised in the questionnaire responses, across all regions. This was confirmed by focus group participants. However, in their view, the issues were more about how CAMHS services are best delivered[42]. The traditional CAMHS model needed to be changed, with more joint working, 'outposting' of mental health workers to frontline services (GP surgeries/schools), and less of an emphasis on the traditional referrals model.

---

[42] 'CAMHS' has 2 meanings that were not properly differentiated in the questionnaire. At the broader level, CAMHS is used to refer to the network of universal and targeted provision made by the wide range of different agencies (and schools). At a narrower level, it is still used to refer to more specialized Child & Adolescent Mental Health Teams, many of whom are still based in Health clinics.

4.105 CAMHS staff needed to participate more fully in the management of difficult cases, and to stay involved even if there was not strong evidence of 'cure'.

4.106 There was concern that some medical interventions (eg use of Ritalin for ADHD) were not sufficiently connected with the inputs from schools and other services.

14+ and post 16

4.107 There were fewer references to FE provision. However, there was evidence that colleges were finding it difficult to provide for young people with the most challenging needs. Little was known about post 16 destinations for this group of young people, with no consistent service follow-up after they reached 16/18.

4.108 It was suggested that planning for young people with these kinds of needs should be more long-term and person-centred, with better support for transitions (as with the other two needs groups). More specific courses and pathways might need to be developed.

Ways in which gaps are being addressed (and examples of positive practice):

Building local capacity

4.109 A number of Authorities were developing more inclusive provision to support children staying locally. Hillingdon has a multi-agency support team that works with young people in BESD special schools and their families to try to prevent placement breakdown. This has led to a reduction in use of out of Authority placements. Cornwall has developed a centre (Nine Maidens) for its most challenging BESD pupils, which provides a limited number of school places, as well as specialised respite. The centre is a focus for the training of specialist foster-parents.

4.110 Dorset and Somerset have developed specialist fostering teams, again with a limited capacity, but focusing on some of their most volatile young people.

4.111 Nottinghamshire has an 'intensive support' team that works to support school and care placements that are at high risk of breakdown. For some very 'high tariff' young people, they also have a 'tailor-made individual programmes' team, consisting of keyworkers who coordinate individualised packages of provision, including inputs from a range of sources[43].

Multidisciplinary support teams

---

[43] Nottinghamshire no longer has BESD special schools, and it has comparatively few out of authority placements. The 2 teams described above are closely linked to 5 Area PRUs that have traditionally offered a combination of off-site support and mainstream outreach provision.

4.112 A number of Authorities are developing multi-agency support teams on a locality basis, in line with national expectations of Children's Services. Some have created teams that focus specifically on the 'heavy end'. For example, in Luton, Education, Health and Social Services have created a pooled budget to target young people most at risk of being placed out of Authority for education/social care/health reasons.

4.113 There is national evidence of a broader range of services being represented in Behaviour Support Teams and Pupil Referral Units.

Complex needs panels

4.114 A number of Authorities (eg Newcastle, Rotherham) have set up joint agency forums where the needs of the most complex BESD pupils are considered. A range of creative options are looked at (and funded) so as to meet children's needs without resorting to out of Authority placement.

Luton Futures: A multi-agency response to meeting the most challenging needs

Luton Futures is a multi-agency project, involving Education, Health and Social Care Services. It is joint funded on an 'Invest to Save' basis. The project is designed to improve local capacity for meeting the needs of children with significant BESD and those with complex learning disabilities who are considered to be most at risk of requiring out of Authority placements.

Developments have included access to local alternative provision where educational placements are breaking down; more flexible use of local residential care options (and better agency support for specialist fostering programmes); as well as intensive/fast-track support for children and families where there are significant and immediate concerns across a range of areas. There is a multi-agency 'threshold' decision-making panel that prioritises referrals.

The initiative has been running for two years and there has already been a significant impact on numbers of young people being placed out of Borough for education, care or health reasons.

Contact: Anne Futcher (Access) or Richard Fountain (Children & Families)

> *Points of Interest*
>
> - *Invest to Save approach funded by Education, Health and Social Care*
> - *Consequent reduction in need for out of authority placements*
> - *Intensive and fast track support for children and their families when concerns raised by more than one agency*
> - *Flexible local care options*
> - *Multi-agency decision-making panel to prioritise referrals and agree provision and resourcing*

CAMHS: new ways of working

4.115 In the Eastern region, there are examples of primary mental health workers now being based in behaviour support teams and extended schools. In Somerset, teams of mental health workers are now operating under the supervision of the Educational Psychology Service.

Keyworkers

4.116 In order to support longer-term planning and continuity of contact with the local community, Somerset has identified a keyworker for every child in its BESD special schools. These people come from a range of backgrounds, including mentors from the wider public.

The contribution of RCEs (regional centres of expertise):

4.117 There were differing views about the place of regional provision for this group of children. On the one hand, it was felt that this would be preferable to placements a long distance from home. On the other, people emphasised the importance of building capacity at a more local level.

4.118 If provision were to be developed for a number of Authorities, it would be better if it were subregional and small. It could offer residence/respite for a small number of very challenging young people. There might be a place for specific specialist provision for BESD girls. However, there had been mixed experience of this model in Newcastle.

4.119 More generally, participants liked the idea of a regional capacity to audit, moderate and monitor local practice, to build on good practice and help strengthen both universal and targeted service responses. There was also a place for regional networking and more coordinated training.

4.120 A regional centre might also play a role in carrying out more coherent evaluations of local interventions and approaches, with a focus on sustainable good practice.

(d) Other areas of low incidence need:

4.121 A number of other LI needs areas were suggested at the end of the focus group events. These included: (i) children with complex health care needs (ii) those with profound and multiple learning disabilities (and challenging behaviour) and (iii) young people with acquired head injuries.

4.122 Generally, participants felt that a number of issues raised in relation to the three main needs areas were applicable to other LI needs (particularly if severity/complexity was a key dimension).

4.123 With these other groups of LI needs, there were some further issues around achieving effective and ongoing links between community health and hospital services and with schools and other related agencies.

Summary of the main findings from the Focus Groups

1) *There was general agreement with the overall questionnaire findings. Focus group discussions allowed further clarification of key issues/barriers affecting local service delivery*

Sensory-impaired:

2) *The main concerns relate to children with multiple difficulties. They include the need for:*

- *Clearer progression pathways and more coordinated planning, particularly at 14+, leading to a better/wider range of local FE options*
- *A broader range of support for emotional/mental health support needs (including better social/leisure opportunities with disabled and non-disabled peers, and a more flexible approach to CAMHS service delivery)*
- *An improved response to care/family support issues, which can be a key factor in parental preference for out of Authority placements.*

There are also concerns with regard to recruitment, retention and training of specialist staff.

3) *Authorities are trying to address these gaps through:*

- *Better liaison with local LSCs and other partners, and broader regional/subregional planning of FE options*
- *Multi-agency transition teams and transition protocols*
- *Improving access to extended care/leisure opportunities*
- *Closer links between specialist workers and CAMHS*
- *Joint commissioning of specialist services and provision*

4) *There was no strong support for the notion of 'regional specialist provision' for this group of children, although some smaller Authorities are happy to share provision on a subregional basis. The main function needed from a regional centre is 'support for building local capacity', which could be achieved through training/advice and more coordinated development planning and monitoring of service quality.*

Summary of the main findings from the Focus Groups (continued):

Autistic spectrum disorders:

5) *The main issues relate to children with severe ASD and significant learning difficulties/ challenging behaviour, and to 'higher functioning ASD children who may be able to cope with the academic demands of a mainstream curriculum, but are at significant risk of social isolation/exclusion. Concerns include the need for:*

- *An improved capacity for joint identification, planning and review, particularly at the point of diagnosis and at transitions (especially child – adulthood)*
- *More/wider opportunities for family support and short breaks/respite*
- *Greater capacity within the mainstream school sector, particularly at the secondary stage.*

6) *Authorities are trying to address these gaps through:*

- *More flexible provision within local services and schools (special and mainstream) in order to cater better for more significant individual needs*
- *Increased opportunities for extended care and leisure activities, with staff more skilled/better trained in responding to ASD needs*
- *More personalised planning for young people at the 14-19 stage*
- *Multi-agency training and increased partnership with parents and the voluntary sector*

7) *Again, there was no strong support for the notion of 'regional specialist provision' for this group of children. In the view of most participants, regional/national centres would best fulfil a research/training role, in order to share, learn from and develop more uniform good practice at local level.*

Behavioural, emotional and social difficulties:

8) *While there are some individual children/young people who present particular challenges, the main issue is the overall 'weight of demand' for services/provision for this group, which makes it difficult to target interventions and resources coherently. Concerns include the need for:*

- *A more common agenda across services and between services/schools to support better collaboration and coordination of responses*
- *A greater number of appropriately skilled and resilient foster-parents*
- *More flexible models of CAMHS/mental health support*
- *Better evaluation of outcomes achieved by different forms of provision (particularly, in the longer-term)*

Summary of the main findings from the Focus Groups (continued):

Behavioural, emotional and social difficulties (cont):

9) *Authorities are trying to address these gaps through:*

- *More flexible/accessible services (eg intensive multiagency support teams) linked to young people whose education/care placements are most vulnerable*
- *Multi-agency decision-making panels, able to target a range of resources at critical points in some children's lives*
- *Development of mental health worker and keyworker roles*

10) *There were differing views about the notion of 'regional specialist provision' for this group of children, with some arguing that this would offer more 'local' provision for some young people whose current placements are a long way from home. The majority of participants preferred the notion of local/subregional provision, offering intensive support to a small number of young people with significant needs. Again, 'regional centres' would best focus on providing an opportunity for training/networking/research and evaluation, in order to support the development of more uniform good practice at local level.*

5.   REGIONAL AND LOCAL PLANNING/DEVELOPMENT (INCLUDING THE POSSIBLE CONTRIBUTION OF 'REGIONAL CENTRES OF EXPERTISE')

> *This section*
>
> - *Provides a summary of the views of national stakeholders and focus group participants about functions/activities that could be organised at a regional/subregional level to support developments in local capacity*
>
> - *Outlines possible options for Regional Centres of Expertise, in the light of the above*

5.1   A range of functions and activities were suggested by national stakeholders and focus group participants that might best operate at a regional/subregional level. These included:

A: STRATEGIC ROLE:

(i)   regional *mapping*: identifying the range of skills and provision available and highlighting gaps/needs for development

(ii)   regional *planning:* jointly commissioning places/provision for more complex needs; joint initiation of project initiatives aimed at addressing gaps

(iii)   *monitoring quality/consistency:* against agreed standards/strategic outcomes and helping resolve issues/problems

Some examples of this function can already be seen in the work of the Eastern SEN Regional Partnership (joint Authority purchasing of places in the independent/non-maintained sector) and of the London Regional SEN Collaborative. The South East SENRP has recently developed standards for sensory support services and this kind of resource could be extended to support regional monitoring.

There were good examples of collaborative strategic planning at a subregional level. In particular, the 3 Dorset Authorities have worked together to carry out a multi-agency review of services to children with learning disabilities (and their families) (see 4.84 above). There has been significant parental and voluntary sector involvement. The review has led to major changes in the way some services are organised and delivered and to a range of new collaborative initiatives. Subregional planning may be more appropriate for regions that are more geographically widespread/ demographically diverse.

B: PROVISION OF SPECIALIST SERVICES:

(i)   carrying out specialised *assessments* (for example, using specialist
         technology/approaches not routinely available)
(ii)   making specific/*sessional provision* (for example, therapeutic inputs or
         child/family leisure activities with peers with similar disabilities)
(iii)   providing *full-time education/respite* for the most severe/complex needs
(iv)   running a *resource centre*, for professionals/parents to try out and borrow
         specialised equipment/resources
(v)   providing specialist outreach services to support professionals in their
         work with children and families more locally

The ACE centres (in Oxford and Oldham) were set up in the 1980s to provide a
focus for the use of technology, to address the communications and educational
needs of children with complex disabilities. Initially, their work has involved
direct assessment of children coming to the centre (centrally funded through CAP
(the Communication Aids Project)). Over time, they have worked to develop
more locally-based multidisciplinary teams (virtual) that can provide more
specialist inputs 'in situ'. Local capacity has been built through clear points of
contact and effective cooperation between key local 'advocates'. Although centre-
based assessments continue, there is now more of an emphasis on supporting local
service delivery, through training, research and loan of materials/resources.

The ACE Centres have tended to focus their work on communication in education
settings, but the model could be extended to support developments elsewhere
(home/care; social/leisure environments) and for children with a broader range of
needs.

There are a number of examples of special schools (both in the LEA-maintained
and independent/non-maintained sector) making full or part-time provision for
children with complex needs. Some have also been a focus for social/leisure
activities (for a broader population). However, there have been some difficulties
in providing this service because of transport costs.

There are also models of special schools providing outreach support beyond their
immediate Authority area (particularly in the independent/non-maintained sector).
Voluntary sector organisations are also increasingly working in this way. The
National Autistic Society has declared its future strategy as being to support the
development of local capacity, with its own school provision being reserved for
those children/young people with the most complex/challenging needs.

C: DEVELOPMENT AND TRAINING:

(i)   *research and development*: trialling and evaluating approaches and
         regional/local initiatives

(ii)   *training:* coordinating training for LI needs across all regional/subregional Authorities, to promote consistency between agencies and areas

(iii)   *support networks:* mutual professional support for people with similar specialist interests

In some regions, Universities/Institutes of Higher Education act as a centre for the development of knowledge and good practice, with regard to particular types of need. Birmingham University has traditionally fulfilled this role in the West Midlands and there are good links between the Education Department and the local SEN Regional Partnership.

5.2   Discussions with national stakeholders and at the focus groups about the potential shape and form of 'Regional Centres of Expertise' (RCEs) revealed a range of different models and emphases. At one end of the continuum, RCEs were seen as a place where children and families could go. Some respondents felt there might be a place for some regional/ subregional specialist provision (for more complex and challenging children with ASD or BESD), to reduce the distance that children were away from home and to support ongoing contacts with home Authorities. At the other extreme, some 'virtual' models involved much looser networks of professionals and other interested parties, which helped support the development of local good practice.

5.3   There were also differences in view with regard to management style. Some would favour a more 'bottom up' approach, with local people joining together regionally for development, motivated by common interests and specific needs. Others (particularly in the strategic category) would favour a more 'top down' model (with high level endorsement by senior managers), aimed at more collective management of difficult issues and ensuring greater consistency and more uniform quality across all local areas.

5.4   Regional Centres might need to operate differently in different parts of the country. The bigger regions tended to argue for some form of subregional organisation, because of the distances involved. It would be possible to link these through 'hub and spoke' or 'satellite models'.

5.5   It was pointed out that RCEs do not have to be 'one place'. Even 'specialist services' such as those described in category B above can be provided in a number of separate locations (or, as the NHS has recently suggested, through 'managed clinical networks').

5.6   It was also argued that RCEs do not have to be based in schools. Clearly, there are some advantages to the link, because of the ongoing day-to-day contact between staff and children. However, there are other examples already existing that are free-standing (for example the ACE Communications Centre in Oxford).

5.7   A key point made across most of the focus groups was that the 'success' of RCEs should be assessed in terms of their ability to support the development of local capacity. There are real dangers of devaluing/deskilling local provision and inhibiting more 'home-grown' initiatives. Those with experience of running regional/national resource centres (eg ACE) have found that these only work if there are 'local champions'.

5.8   Centres of expertise need to be learning organisations. They are likely to be less effective if they are too insular or rely too heavily on existing knowledge. As one respondent commented, *'being an expert is knowing what you don't know, having an open mind, and being prepared to keep on learning'*.

Regional Centres of Expertise (RCEs):   *options for development*:

5.9   A matrix summarising the range of options for RCEs and their potential advantages and disadvantages is shown in Table 2 (below). The matrix also shows the level of support for each model given by stakeholders in both national and local/regional discussions, and also an assessment of financial costs.

5.10   The overwhelming view from the focus groups was that *all* Authorities needed to develop their own capacity. Regional Centres should be designed to support local improvements rather than being an alternative to local provision. The only exceptions to this view were the possibility of some specialist provision operating on a *subregional* basis, as already happens in some areas, and the potential benefits of developing regional/subregional provision for the most severe/ challenging needs, so that children did not have to be placed residentially, a long way from home.

5.11   The predicted costs of developing new Regional Centres (where children and families go to receive services) are likely to be high. Existing provision could be adapted to perform a different role, but this would need to be designed as part of a broader regional strategic approach involving all relevant stakeholders. Considerable strategic planning would be necessary to 'recommission' services and provision at regional level, which could not be done in isolation from developments at individual local authority level.

5.12   There was a greater level of support for RCEs as 'Resource Centres', offering training and development opportunities across a wider area. A number of centres could be identified within a region, linked to specific needs groups. However, these would need to work within broader strategic priorities, agreed across the region as a whole.

TABLE 2:   REGIONAL CENTRES OF EXPERTISE

Possible models and functions, their potential advantages and disadvantages and the degree to which the different models were supported by audit respondents

Model	Possible Functions	Potential Advantages	Potential Disadvantages	Level of support	Costs
Regional/subregional school for specific categories of need	Full-time education for small number of low-incidence/high cost pupils Research and development of specialist skills/materials/ strategies and programmes Support for development of local provision and skills through outreach services	Economy of scale for smaller authorities (for pupils who need 24 hour/52 week placement) Provision of specialist approaches/therapies is more readily available Experience and skills for teaching, managing and supporting pupils with particular kinds of needs can be developed	Pupils educated away from their homes and local communities Less opportunity to develop local provision and skills Difficulties in re-integration at a later date and more likely to lead to need for specialist post-16 placement	LOW Some support for specialist school provision for a very small number of highly challenging ASD/BESD and severe and complex multi-sensory	HIGH (if new provision); Would be more financially viable if it arose from strategic 'recommissioning' of provision at regional level

Model	Possible Functions	Potential Advantages	Potential Disadvantages	Level of support	Costs
Regional/subregional Resource Centre (generic)	Central information base regarding available research, materials, equipment, access to funding etc	Service providers can readily access up-to-date information on national/regional and local developments	Possible difficulties regarding funding, management, and staffing	MEDIUM/HIGH	MEDIUM/HIGH
	Team of regional/subregional support teachers with expertise to help teachers design appropriate teaching programmes (communication experts, specialist inclusion practitioners, anti-bullying consultants, technicians etc)	Skilled and knowledgeable support for local providers would lessen risk of pupils requiring specialist/ alternative/out of authority provision	Would require very clear remit, management and working arrangements to ensure efficient, effective and equitable delivery of services across the region/subregion		
	Central resource base for very specialist resources/curriculum materials/ICT programmes/ high-cost equipment	More effective and efficient use of high-cost resources, which can be distributed when and to where they are needed	Does not resolve the problem for small authorities of finding suitable 'maintained' placements for the small number of 'very hard to place' children		
	Forum for sharing practice	Potential for multi-agency office base			
	Support for local authority service providers through staff training programmes and support and training for parents	Centre for parent support meetings/events			
	Forum for offering a range of services, as detailed below	Greater consistency in skill development through centralised training programmes			
		Could provide secondment opportunities to Local Authorities to assist in the development of in-house skills/capacity			
Model	**Possible Functions**	**Potential Advantages**	**Potential Disadvantages**	**Level of support**	**Costs**

Regional /subregional Centres with specific remits	Named locations each offering a particular services for different low incidence or very complex needs. These might include: -diagnostic assessments -therapeutic inputs -child/family leisure/sporting activities with peers with similar disabilities -training programmes for service providers and parents Research and development: trialling and evaluating approaches and regional initiatives	Building on, broadening and making effective use of existing service providers and locations (specialists within EPS/CAMHS/ voluntary agency services/Child Development Centres, Health Centres/Youth and community centres etc) Named local authority services with existing skills and experience could extend their 'development' remit to take on regional/subregional responsibilities for particular aspects of training, or for research and development	Might result in a less co-ordinated approach than having a Resource Centre with a broad remit Possible difficulties regarding funding, management, and staffing Would require very clear remit, management and working arrangements to ensure efficient, effective and equitable delivery of services across the region/subregion Difficulty in responding to changing patterns of need	MEDIUM	MEDIUM/HIGH

Model	Possible Functions	Potential Advantages	Potential Disadvantages	Level of support	Costs
Virtual provision	Collaborative arrangements within the region/subregion to undertake specific strategic tasks: These might include: -regional *auditing and mapping* of skills/provision/gaps/needs for development -regional *planning* for joint commissioning and joint projects for improving local practice -regional *monitoring* for quality and consistency against agreed standards/strategic outcomes Collaborative arrangements between local authorities to share expertise, where needed, for specialist skills and practical support Collaborative arrangements for research and development (trialling and evaluating approaches and regional initiatives) Networks of named/interested professionals within local authorities able to support the development of local good practice	Would not require a physical centre incurring accommodation costs etc Would ensure greater consistency in the development of local provision Relevant people/agencies could be tasked to carry out different activities Would enable provision to be regularly monitored, adjustments to be made in the light of changing needs and common priorities to be identified Might make more efficient use of available expertise within the region Would build on existing good practice in some regions/authorities Would build on existing networks supported by SENRPs and facilitators Opportunities for secondment of range of staff to assist research/development and strategic planning	Would require secure arrangements for funding activities on a regional basis (meetings, research and development work etc) Does not resolve the problem for small authorities of finding suitable 'maintained' placements for the small number of 'very hard to place' children Not a physical entity/difficult to identify as a 'centre'	HIGH	LOW

5.13 A lower cost option would be the development of more effective networking within each region. Opportunities already available could be extended and enhanced by stronger strategic coordination at regional level and clearer links between regional and individual local authority priorities. The DfES would need to outline a clear agenda to be covered regionally, with timescales for action. This could include the development and monitoring of quality standards for particular LI needs groups (linked to broader ECM outcomes), identification of key development needs, both across the region as a whole and within individual Local Authority areas, and planning for improvement.

5.14 Considerable thought would be needed with regard to the relative contributions of Local Authority representatives, SENRP facilitators, link SEN national advisers, and other regional advisers/development staff in these developments. There would need to be both challenge and support to individual Local Authorities in pursuing appropriate improvements, and the development of a 'collective culture' across Authorities and the range of agencies that recognised the importance of progress towards more consistent levels of good practice. The existing SENRP steering groups (which involve a range of relevant stakeholders) could be developed to provide a much broader multi-agency forum for monitoring/overseeing relevant developments within each region.

Key points in relation to regional/local planning:

1) *Regional/subregional functions and activities need to support the development of local capacity*
2) *Local capacity developments are most likely to be supported by:*
   - *Strategic planning/review*
   - *Quality monitoring*
   - *Research and development*
   - *Networking and training*
3) *The majority of focus group participants and national stakeholders interviewed favour a 'virtual model' for Regional Centres of Expertise, rather than one centre/regional specialist provision*
4) *Regions, individual Local Authorities and other partners need to be closely involved in identifying local/subregional/regional good practice and relevant sources of support/expertise in their area.*

6. OVERALL SUMMARY OF FINDINGS AND IMPLICATIONS FOR DEVELOPMENT[44]

> *This section*
>
> - *Provides an overview of the key findings from the Audit as a whole, building on the responses to the questionnaire, focus group discussions, and the main themes derived from the initial scoping stage*
> - *Summarises the implications for regional/local development*

6.1 The audit has shown a significant level of agreement about key issues and development needs.

6.2 A similar picture has emerged across all sources of evidence (scoping interviews, literature review, questionnaire responses and focus group discussions), lending further support to the validity of the findings.

6.3 While there are some differences between the three main groups (Sensory/ASD/BESD), in the issues they present, there is also a high degree of commonality, particularly at the severe end of the continuum, where needs are more complex and multiple. There are also similarities in relation to other types of low incidence needs (such as physical/health care and profound/multiple learning disabilities).

6.4 ASD and BESD issues are regarded as more challenging, compared to the area of sensory/multisensory impairments. However, in the latter, there are concerns about recruiting and retaining practitioners with relevant expertise.

How Local Authorities meet the needs of children with low incidence SEN

6.5 Local authorities generally seek to maintain a continuum of provision for children with low incidence needs. For those with more severe/complex needs, most Authorities make some use of provision outside their area. However, the level of use of out of Authority placements varies significantly across the country.

6.6 Authorities generally have some level of specialist services and provision to meet low incidence needs, in terms of education support teams and mainstream unit/ special school provision. However the shape and form and the extent of these varies.

6.7 Even where there is dedicated educational provision for particular types of low incidence needs, this does not always cover the full range of individual pupil difficulties. Difficulties are experienced in providing effectively for children with

---

[44] Linked to the project specification

90

more complex and multiple difficulties, who can have needs across a number of different dimensions.

6.8   Social care/family support services are generally less differentiated, although there is some evidence of increasing specialisation in some areas of the country.

6.9   Health Authorities provide a range of therapy services for children with low incidence needs, but the capacity of these varies. There continue to be significant recruitment issues in some areas. Therapy services are looking to develop more cost-effective ways of service delivery that will enable their support to be better targeted.

6.10   Children with low incidence needs should have access to a range of other types of service (eg Youth Service, Connexions, CAMHS). However, there was evidence of some barriers in these areas of provision.

6.11   In most Authorities, there appear to have been improvements in the delivery of services and support in the early years, and these are being reinforced by the Government's Early Years Support Pilot Programme. At the other end of the age scale, there are a number of specialist colleges that focus on particular kinds of low incidence needs. The voluntary sector and the LSC are keen to promote better access and opportunities for such students in their local area, through improvements in the mainstream FE sector.

6.12   Authorities assess the quality and appropriateness of their services, support and provision in two ways: at the individual pupil level, through statutory reviews and support service monitoring. Different agencies and areas also make use of consumer feedback from parents, schools (and sometimes from young people, directly). At a broader level, agencies and services are developing different ways of self-evaluation, and schools are increasingly required to evaluate outcomes and seek parental views.

6.13   A number of Authorities are starting to review their services and provision more holistically, involving a broader range of stakeholders in identifying issues and ways forward. The Pan Dorset review cited as a vignette earlier in this report is a good example of a systematic approach that has led to more coherent and collaborative planning for the development of a range of local services.

6.14   In the area of sensory impairment, Authorities are starting to make use of the national standards published by the DfES (2002) and more detailed assessment approaches are currently being developed in the South East region.

6.15   There is evidence that clearer national guidelines for good practice would be welcomed as a basis against which local quality can be judged more systematically. These will need to go beyond process and start to define desired outcomes across the range of Every Child Matters dimensions.

Gaps in services, support and provision and how these are being/could be addressed

6.16   The key gaps in service, support and provision for these three groups are not in relation to specific skills and interventions, but to the broader areas such as family support/respite care, support for mental health issues, and better social/leisure opportunities, where greater skills and capacity are needed. Priority needs to be given to developments in support and provision for older children as they move towards adulthood.

6.17   The task is not to improve individual elements of provision *in isolation*, but to develop more coherent packages of support that address all aspects of children's lives. For children with severe low incidence needs, joined-up responses are the key to making local provision more inclusive and effective.

6.18   There are encouraging examples of good practice at local, regional/subregional and national level that could be built on and extended.

6.19   Provision for more complex difficulties has to be supported by improvements in universal provision for the broader continuum of special educational needs.

6.20   There is also a need for significant development in the mainstream secondary school sector. Difficulties experienced in this context are leading to placement breakdown for some pupils with low incidence needs who, with better support, should be able to access the broader curriculum.

6.21   Planning for 14+ progression needs to be better informed and more person-centred, and involve all relevant services. In some areas, more specialised knowledge and specific skills are needed within generic services (such as Connexions).

6.22   There is a priority need for development in local FE college provision. More strategic planning of college provision (and proper funding of support) will be needed to ensure that students with low incidence needs are better catered for.

6.23   There are new opportunities within the further education sector for improving local provision, in the light of strategic changes within the Learning & Skills Council and the recent publication of the Little Report. This should create greater capacity for local/regional developments. However, there are some continuing barriers to progress in that sector, such as funding for transport.

6.24   Child and Adolescent Mental Health Services (CAMHS) need to be more accessible to young people with low incidence needs. There is evidence that disability access should be improved (for children with sensory impairments and/or complex learning disabilities). There is also a call for changing patterns of

support for mental health issues, with specialist workers linked more closely to frontline professional staff.

6.25 Gaps in family support and short break/respite provision come out very strongly from this Audit. These are a major factor in parents/carers opting for placements away from home. There are also limits in the availability of suitable extended day/social and leisure opportunities, which puts further pressure on families and restricts the range of some young people's experiences.

6.26 Local authorities find it more difficult to meet needs when young people have multiple impairments or issues that cut across a range of service/provision boundaries. This argues for more flexible service responses that are more child-centred and responsive to individual needs. Local Authorities also appear to have more difficulties when their special provision is based on traditional categories. More generic 'complex needs' provision tends to mean that fewer children 'fall through the net'.

6.27 Generally, Local Authorities find it more difficult to meet needs locally where there are significant behavioural issues, and where provision is breaking down on a number of fronts (school/home/community). However, there are also a number of children placed out of their own area where there are differing views between parents/carers and statutory services about the ability of local provision to meet their child's particular needs.

6.28 In relation to services/provision for young people with <u>severe/profound sensory/multisensory impairment</u>, Local Authorities are trying to address the gaps through:

- *Better liaison with local LSCs and other partners, and broader regional/subregional planning of FE options*
- *Multi-agency transition teams and transition protocols*
- *Improving access to extended care/leisure opportunities*
- *Closer links between specialist workers and CAMHS*
- *Joint commissioning of specialist services and provision*

6.29 For those with <u>severe/complex autistic spectrum disorders</u>, the priorities have been to develop:

- *More flexible provision within local services and schools (special and mainstream) in order to cater better for more significant individual needs*
- *Increased opportunities for extended care and leisure activities, with staff more skilled/better trained in responding to ASD needs*
- *More personalised planning for young people at the 14-19 stage*
- *Multi-agency training and increased partnership with parents and the voluntary sector*

6.30 For those with severe/complex behavioural, emotional and social difficulties, Local Authorities are seeking to address the gaps through:

- *More flexible/accessible services (eg intensive multiagency support teams) linked to young people whose education/care placements are most vulnerable*
- *Multi-agency decision-making panels, able to target a range of resources at critical points in some children's lives*
- *Development of mental health worker and keyworker roles*

Implications for regional/local planning and development (and RCEs)

6.31 There is evidence from this Audit of a considerable amount of expertise available across a wide range of providers (LEA-maintained schools, support services, statutory agencies, voluntary organisations and the independent/non-maintained sector, not forgetting the experience, skills and perspectives developed by parents/carers and young people themselves).

6.32 There are a wide number of ways in which this expertise could be better directed. However, the overriding emphasis emerging from this Audit is that it should be used to enhance and support local capacity, to skill and not to deskill, and that it should be part of a broader culture of continuing development across all relevant services.

6.33 Extension of expertise would be supported by more effective processes of local, subregional and regional planning (for example, through more systematic mapping of development needs and skill shortages, identifying local/regional resources and improving coordination of developments, so that these can draw on the strengths of a broader range of providers).

6.34 Generally, the Audit points to the need to strengthen generic provision and services, using specialist expertise in a developmental way. There is not a strong push for the creation of more and more specialist facilities. However, there is a need to ensure that specialist skills continue to be available and that sufficient specialist staff can be recruited and trained.

6.35 There is little overall support for the development of regional centres of expertise in terms of specialist 'provision for children', except in a very limited capacity. However there is general support for improved regional and subregional planning and review to ensure more consistent levels of good practice, and more coordinated opportunities for networking and training.

6.36 The Audit ch allenges the view that expertise has intrinsic value. Its usefulness needs to be measured in terms of its contribution to building local capacity, so that *all* children with low incidence needs can benefit. This implies that expertise

is best delivered through effective training and networking opportunities, rather than being 'held' in a centre at a distance from day-to-day practice. There is clearly an important place for research and development, but this needs to be connected with and informed by practice issues. There is also a continuing place for direct service provision of a specialist kind, but there should always be a clear emphasis on extension and generalisation of good practice to a wider range of providers.

6.37 Nationally, there needs to be a coordinated programme of research and development linked to key areas of low incidence needs, with proper dissemination and close links with the range of stakeholders. Good practice examples need to be made available, particularly those that include children with more complex needs and that make effective use of expertise to enhance local provision.

6.38 Regionally, the range of relevant expertise available needs to be mapped and better coordinated to provide more consistent training opportunities for all agencies. Regions should continue to support networks and interest groups, drawing together staff from statutory agencies, voluntary organisations, parents and the independent/non-maintained provider sector.

6.39 Locally, expertise could be supported and extended in a similar way. The Audit indicates that there have been significant benefits where different services have come together for multi-agency training, so that there are better common understandings and a common language/repertoire of approaches available.

6.40 A number of ways forward are outlined in the Recommendations section of this report. The Audit indicates that developments in each area should be based on a coherent and coordinated assessment of current services and provision, against clearer national standards. Regional developments need to support the building of local capacity, so that good quality provision is available more consistently locally for all children with low incidence needs (and particularly those most at risk).

The feasibility of auditing specialist services, support and provision on a regular basis

6.41 The National Audit has been productive and a wide number of stakeholders have been engaged. However, obtaining a comprehensive picture has been labour-intensive. Moreover, the wide scope of its remit has meant that the focus has inevitably been on broader and more general issues. While it may be important to revisit these at a future date (in 5 years time) to assess the degree of progress in meeting current gaps, a more immediate priority is to support the process of more locally-based reviews.

6.42   These should draw more heavily on consumer experience (parents/carers and young people themselves) and identify more specific points for development at local/subregional/regional level. The process of the Pan Dorset review (described in 4.84 (above) points to a possible way forward.

7. RECOMMENDATIONS:

7.1 The DfES should give a clear steer to regions and Local Authorities with regard to good practice for children with low incidence needs, through publication of this report and active dissemination of its findings. The report should be discussed by relevant regional stakeholders and an action plan developed at this level. The regional SEN link advisers should follow up the particular gaps/areas for development identified in this report, through their contacts with individual Local Authorities, in order to monitor progress.

7.2 There should be local discussions within regions to establish which action points are best progressed at regional, subregional or individual Local Authority level. This will vary depending on demographic factors, existing strengths and local priorities.

Addressing the gaps:

Secondary mainstream school and post 16 inclusion:

7.3 The DfES should strengthen its expectations of inclusive provision in *all* secondary mainstream schools. It should fund research into effective models of inclusion at this phase and identify/disseminate good practice. Consideration should be given to the most effective ways of managing mainstream SEN units/resource bases for children with low incidence needs, so that these promote local inclusion and do not undermine the need to develop and improve universal provision.

7.4 The Government should implement the recommendations of the Little Report on provision for students with disabilities in FE colleges. This emphasises the need to organise funding to support and plan for better local opportunities within the mainstream FE sector. The LSC nationally should identify and promote positive examples of good practice, particularly in relation to those students with the most complex needs. In addition, greater consideration should be given to transport issues and the possibility of extended courses. Gaps in these areas tend to act as barriers to local provision for some students.

7.5 Regionally and subregionally, links should be made with local Learning Skills Councils, to start to plan improvements in practice and to develop the range of educational and vocational pathways that young people with low incidence needs can follow from 14 onwards. Provision should be planned more strategically, across the local FE sector, so that specialised courses for groups of students can be focused in particular colleges, where this is desirable and appropriate.

Transition planning:

7.6   The DfES and the Department of Health should review their overall approach to 14+ and 16+ planning, to ensure these are properly linked, that they encourage a more holistic person-centred approach and gives appropriate weight to longer-term issues. Further training and support should be provided as necessary through the existing Valuing People initiative. Positive approaches to involving young people in planning for themselves and supporting others with similar disabilities should be actively disseminated.

7.7   The DfES should provide a stronger lead to Connexions in supporting the transition process for young people with complex disabilities, and in ensuring that Connexions staff have the relevant skills and knowledge to do this.

7.8   At Local Authority level, agencies should work together with schools, parents and other relevant partners to ensure that all relevant information is shared across points of transition and is used by future providers.

Support for mental health issues:

7.9   The Department of Health should continue to support the CAMHS modernisation process and encourage new models of working. Particular attention should be given to the ways in which CAMHS can best be integrated within the new local Children's Services, to enhance and support their work. The Audit suggests that there is much to be gained by linking mental health workers to more frontline support agencies (as well as providing consultancy support to professionals at Tier 3).

7.10   Regional Development Workers (CAMHS) should review the accessibility of existing CAMHS services to ensure there are no barriers for young people with disabilities. Active consideration should be given to reducing the need for specialist Tier 4 services, which currently require some young people with low incidence needs to attend provision a considerable distance from home.

7.11   Local CAMHS services should work more flexibly to ensure that support for mental health issues is available to all young people with low incidence needs who require such help.

Other therapy provision:

7.12   The Department of Health should continue to address recruitment issues (for example for Speech & Language Therapists). Strategic Health Authorities should work with Primary Care Trusts to ensure that there is sufficient capacity available to address needs locally. Local Therapy Services should be encouraged to make cost-effective use of their resources, linking with other partner agencies within the

new Children's Services so that the best use is made of all the resources that are available.

Short break/respite care/extended day opportunities:

7.13 The DfES and the Department of Health should work together to extend the range of short break options for young people with low incidence needs and to disseminate good practice. In particular, the DfES should ensure that the development of extended day provision is inclusive of those with more complex difficulties (proper consideration is needed of transport and additional staffing issues).

7.14 The Department of Health should review the impact of its Direct Payments scheme to establish how far this has helped/hindered the development of more suitable short break/respite options.

7.15 Regionally and subregionally, a pool of suitable foster-placements should be developed. Foster-parents should be given the training and support needed in order to cater for young people with particular low incidence needs, and they should be properly remunerated for this complex task.

7.16 Local Authorities should work together and with the voluntary sector to provide a better range of social/leisure opportunities, that are more accessible to young people with low incidence needs and enable them to form relationships with others with similar disabilities, where this is what they would like.

7.17 Local Authorities should review their short break/respite services, drawing on the views and experiences of parents and young people, to ensure there is a better range of options more closely linked to family needs.

Specialist staffing:

7.18 The DfES and the Department of Health should monitor recruitment to and the availability of specialist posts for low incidence needs. Where there are shortages, it should liaise with Local and Strategic Health Authorities, and with training institutions, to develop alternative pathways or appropriate incentives.

7.19 Regions should consult their Local Authority areas to establish whether there might be economies of scale or other service delivery benefits from regional/subregional management of some specialist services.

7.20 Local Authorities should work with their specialist providers (such as Specialist Support Teaching Services) to ensure that existing patterns of staffing are best suited to the tasks that are required and are linked into a more integrated approach to service delivery.

7.21 Strategic planning is needed at regional, subregional and local levels. The balance will need to be decided within each region. However, it should take place within a clearly articulated national framework, linked to Quality Standards.

Standards

7.22 There is currently a range of standards for provision and services (for example, within the SEN Code of Practice, Removing Barriers to Achievement, OfSTED, National Service Framework (Disabled Children), Every Child Matters and Quality Protects). The DfES should bring these together within a unitary framework[45] that is accessible to all relevant providers. The framework should be clearer in its principles and recommendations (in particular, the importance of provision being made locally wherever possible; and the value of a multi-agency approach to planning and delivery of services). It should cover desired outcomes (linked to Every Child Matters) as well as processes, and ensure that it encompasses all relevant services (including Health).

7.23 The DfES should consider extending the existing standards for services for sensory-impairment (DfES 2002) to include a broader range of outcomes/service areas and a similar approach could be taken to other areas of low incidence need.

7.24 SEN Regional Partnership coordinators/facilitators and other regional development staff should monitor and support the development of this Quality Framework at individual Local Authority/Children's Service level. They should work to disseminate examples of good practice.

7.25 Local Authorities/Children's Services should set up a working group, involving a range of stakeholders (agencies, voluntary organisations, and parents) to decide how they will interpret and address the Quality Framework at local level, and to prioritise its application to particular 'risk groups'.

Audit/review/monitoring

7.26 The DfES should encourage the systematic and regular collection and analysis of information at local and regional level, regarding the needs and welfare of children and young people with complex needs, and their families. Such information should include education, health and social care data. Government Departments should link more closely together to ensure nationally-collected data is relevant and shared across all agencies.

7.27 The DfES should seek information, through discussion with regional and local bodies, OfSTED and its national advisers, about the continuing gaps/issues

---

[45] or extend NSF

experienced in meeting the Standards outlined above, and this should be included in the focus for Joint Annual Reviews.

7.28 Each Region should establish a steering group involving relevant regional development/advisory staff, Local Authority and Strategic Health Authority managers and the voluntary/independent sector in order to audit/monitor progress, provide feedback/challenge/support to individual Authority areas where there are particular issues and identify areas where regional/subregional developments would be particularly beneficial.

7.29 Local Authorities should review their existing services for low incidence needs, against the nationally available Standards, drawing on the experience of a range of stakeholders, including parents/carers and young people themselves.

Development

7.30 The DfES should use this report as a basis for prioritising developments for low incidence needs. It should monitor progress over the next 5 years, in relation to the key gaps identified.

7.31 The Government should consider providing financial support for 'invest to save' initiatives within regions/individual Local Authority areas that will help strengthen local provision for low incidence needs, as an alternative to placements further afield.

7.32 Regional steering groups should have regard to the priorities identified and include these in their development plans. They should disseminate/share emerging good practice, where there is evidence of significant progress in meeting low incidence needs or where there may be opportunities for generalisation to other parts of the country.

7.33 Regions should consider allocating some of their Regional Centre of Excellence funding to support the development of local capacity, linked to the priorities identified above. Regional working groups should also be consulted when the DfES is considering according specialist status to individual special schools within their area. Criteria for this decision should include the ability of the special school to make a significant impact on the development of capacity at the individual Local Authority level.

7.34 Individual Local Authorities/Children's Services should prepare development plans for improving services to young people with low incidence needs and their families. Plans should take account of the main priorities/gaps in service/ provision that have been identified through the national Audit and through any more local reviews.

Flexibility and collective responsibility

7.35   The DfES should support the movement of special schools towards more inclusive practice that is less defined by traditional categories. Through its advice and inspection arrangements, it should foster a more 'open' role where special schools are willing and able to adjust their provision to meet changing local needs and support the strengthening of local options, so that children do not need to be placed out of Authority.

7.36   The DfES should also encourage flexibility in the services and support provided by statutory agencies. It should support the development of joint accountability for outcomes (linked to the Quality Standards Framework).

7.37   Regional steering groups should work closely with their Local Authority areas to find ways of addressing current and future gaps in provision, drawing on cross-Authority initiatives and positive practice in individual Authorities/agencies.

7.38   Individual Local Authorities/Children's Services should consider the potential benefits of working together with other Areas, to promote greater consistency in good practice and mutual learning.

7.39   Individual agencies and services should give priority to collaborative working, particularly with those young people who present the biggest challenges and who are most likely to need a highly coordinated approach. Local Area 'Prioritisation Panels' appear to be an effective way of targeting local services and support on those young people/ families that are most at risk of out of Authority placement.

7.40   Voluntary sector and independent/non-maintained sector providers should follow the lead set already by organisations such as the RNIB, SENSE and the National Autistic Society, in seeking to develop their traditional emphasis on specialist provision in order to support the growth of more consistent local capacity across all regions of the country.

Regional Centres of Expertise

7.41   In our view, given the DfES's commitment within the Removing Barriers strategy to develop Regional Centres, there will need to be some clear investment in this direction.

7.42   One option would be to link RCEs to the programme already initiated to develop specialist special schools (where additional funding is already being made available). The problems with this option are as follows:

   (i)   The programme currently links exclusively to schools providing for secondary-aged pupils

(ii) There is not a clear linkage between the criteria used so far for identifying specialist schools and regional/individual Local Authority needs[46]

(iii) The Audit has strongly indicated that developments are needed in *all* Authorities. RCEs need to be able to show clearly how they are supporting local developments/capacity (and that they have the skills to do so).

(iv) Insofar as regional specialist provision *is* indicated, it needs to be for those pupils with the most significant/complex/challenging needs. The current criteria for according specialist status do not necessarily take level of severity of need into account[47].

7.43 An alternative low cost option would be to provide a small amount of money to each region to support/pump-prime improvements in local capacity for meeting severe/complex LI needs. Initiatives would have to demonstrate how they were going to address the key issues identified within the National Audit. They would need to be capable of extension across the region as a whole and ultimately be self-financing. They could include the development of (physical) centres, if this was consistent with both regional and local priorities, and the more systematic sharing of good practice across Local Authorities within the region.

7.44 The advantage of this model (apart from cost) would be in the flexibility available to each region to determine local needs and priorities (and ways forward). It could also strengthen links between regional and subregional/local planning. The main disadvantage to such a 'virtual' model is that it may not match the expectations of a 'physical entity' that 'regional centres' imply.

7.45 A third option would be to draw together the development of specialist special schools and other LI initiatives within a more coordinated strategic regional planning framework. This could draw together a range of relevant stakeholders (SENRP facilitators, national SEN advisers, regional change advisers, local authority representatives, the voluntary sector) in identifying the priorities most likely to achieve local improvements. These could form the criteria against which 'specialist status' and funding of development initiatives could be allocated. This would be the option we would favour. It would link into the new structures and organisation within Regional Government Offices and could derive ongoing development funding from Regional Centres of Excellence budgets.

---

[46] The distribution of specialist schools is currently very uneven across regions and categories of need.
[47] In the area of BESD, for example, there is some evidence to suggest that those schools with the most challenging pupils are most vulnerable when it comes to negative Ofsted inspections.

NATIONAL AUDIT OF SUPPORT, SERVICES AND PROVISION FOR CHILDREN WITH LOW INCIDENCE NEEDS

Appendices

The
Special
Needs
Consultancy

APPENDIX 1:   DFES PROJECT SPECIFICATION + PROJECT SUMMARY

(i) <u>Expected outcomes:</u>

    a. An overview of the findings from the audit at national level

    b. Identification of specialist expertise, services, support and provision available for children with low incidence needs at the local level; and how they could be shared regionally eg information, resources, expertise etc.

    c. Identification of gaps in specialist services, support and provision and what special needs individual authorities find it difficult to meet within the authority.

    d. How individual authorities and/or regions address this issue of unmet needs and what do they need to meet them.

    e. How these needs could be met via a local or regional resource.

    f. How authorities assess the quality and appropriateness of their services, support and provision for children with low incidence needs.

    g. The feasibility and value of auditing specialist provision on a regular basis and how regular this should be

    h. Advice on how this expertise could be better used at national, regional and local level and what would need to happen to facilitate this

(ii) <u>Project summary (*circulated to participants*)</u>

DfES National Audit of provision for children with Low Incidence Needs

Introduction

Peter Gray and a team of colleagues from the Special Needs Consultancy are undertaking the Audit. The work was originally proposed in the SEN Strategy 'Removing Barriers to Achievement' 2004, and is intended to impact upon the establishment of Regional Centres of Expertise for LI needs.

Context

The Government's commitment to carry out a national audit of low incidence SEN provision has arisen for a number of reasons:

   (i)   Concerns have continued to be expressed by some voluntary organisations and others about the availability and consistency of support available across the country for pupils with low incidence needs (such as autism and multi-sensory

impairment). The lack of suitable local provision means that the needs of some pupils may not be fully addressed or they may have to be educated in specialist settings at a significant distance from the family home.

(ii)   Local authorities have expressed concern about the high costs of out of area provision, particularly residential placements in the independent/non-maintained sector. Many LEAs would also like to see pupils educated more locally, and to develop greater local capacity to provide for children who are currently placed elsewhere.

(iii)   Some Local Authorities report significant difficulties in retaining specialist provision, skills and expertise for pupils with low incidence needs because of a lack of 'economies of scale'. Smaller Authorities, for example, may only be able to employ one teacher for the visually impaired. In such areas, there may be restricted opportunities for the further development of specialist skills and limited cumulative experience of the needs of pupils with more complex and unusual difficulties (e.g. multi-sensory impairment).

A definition of 'low incidence'

It is important to have a clear definition of what is meant by 'low incidence' needs. This is not simply an issue of 'rarity' (for example, of particular physical/medical conditions). The definition needs to be more *functional*, with the emphasis on the complexity of the task of supporting and providing for the young person and the nature of the skills and organisation that are required to ensure that all their needs are properly addressed.

The DfES has identified a number of categories of low incidence needs that are relevant to this study. These include:

- (a) multi-sensory impairments
- (b) severe visual impairment
- (c) severe/profound hearing impairment
- (d) profound and multiple learning difficulties
- (e) severe autistic spectrum disorders and/or
- (f) severe behavioural, social and emotional difficulties

The emphasis on 'severity' is important here, as sensory impairments in themselves are not uncommon or 'low incidence', either in childhood or later on in life. Similarly, while teachers encounter a range of pupils presenting behavioural, social and emotional difficulties, there are a small number whose difficulties are so severe and complex that they present challenges, not just to schools but also to the range of professional agencies and support services who seek to provide for their needs.

Process/methodology

The audit is progressing through three stages:

1. Scoping
2. Piloting
3. Formal national audit

The main strands of the audit involve:

   (a) a national questionnaire, to be completed by representatives of statutory agencies in each Local Authority area, and
   (b) focus groups organised in each region/subregion

The Audit team is liaising closely with the relevant SEN Regional Partnership Coordinators.

The Audit of LI needs in the London area is linking closely with a parallel exercise that has been commissioned by the Association of London Chief Education Officers (ALCEO) and the London Challenge. This aims to provide a detailed analysis of all kinds of out of Authority placements (including provision in day/other LEA-maintained special provision as well as in the residential/ independent/non-maintained sectors). The Special Needs Consultancy is also carrying out this work, which will run over the same timescale as the National Audit. Careful planning is under way to ensure that the 2 projects are properly integrated and manageable at the local authority officer level.

Following initial consultation and piloting, the **Questionnaire** is now being sent to all English LEAs, with 3 versions to be completed by relevant officers/managers in Education, Health and Social Services.

Respondents (or other suitable local representatives) are also being invited to regional or subregional **focus groups** (in Sept/early Oct), which will also include relevant representatives from the voluntary and independent/non-maintained sector and other key people from the region (e.g. regional advisers (Change; Quality Protects; CAMHS)). The Audit team is currently working with SEN Regional Partnership colleagues and others to develop a list of relevant contacts.

The agenda for focus groups will be as follows:

1) To receive an overview of questionnaire responses in the region (and link this to what is already known/emerging at regional/subregional level from other relevant sources)
2) To identify the specific issues and gaps regarding the key areas of low incidence need covered by the audit
3) To draw on the perspectives of key stakeholders in the region, including representatives from LAs (Education &Social Services), Health, and the voluntary and independent/non-maintained sectors
4) In the light of the above, to consider possible options/models for the operation of regional resource centres/centres of expertise.

APPENDIX 2:   METHODOLOGICAL DETAILS

a) Scoping Review:

The scoping review was mainly undertaken in Spring Term 2005, at an early stage in the project. It consisted of a range of interviews with key national stakeholders. These included officers from the relevant Government Departments (DfES/DOH), national representatives from a wide range of voluntary organisations, from local authorities and from the independent/non-maintained school sector. An early meeting was also held with all of the SEN Regional Partnership facilitators.

A literature review was carried out covering the main types of low incidence needs identified above. Sources included key Government publications, key texts (books/journal articles) and research reviews for each area of need, and material from the relevant voluntary organisations. The review is included as Appendix 3 to this report.

In addition, discussions with DfES Analytical Services officers, the SEN National Advisers and the SEN Regional Partnership team generated a range of relevant data/resources. This included data on 'out of Authority' SEN placements (in the independent/non-maintained sector) and reports from other SENRP initiatives[48].

The research team were alerted to other reviews initiated or completed during the period of the national Audit. These included a study of disabled children in residential placements by Anne Pinney (recently published) and the National Child Health Service Mapping exercise (covering a broad range of Health services for children with disabilities).

The research team were also allowed access to relevant sections[49] from the reports of the SEN National Adviser visits to all English LEAs[50].

b) Questionnaire:

Design decisions:

The questionnaire was a key element in the original project specification, and the DfES was keen to ensure a high return rate, so that a clear picture could be obtained across the country as a whole. In order to maximise the return, a number of design decisions were made and agreed at the initial project steering group meeting:

---

[48] A review of low incidence SEN in the Merseyside region (1999); A review of placements of children with very specialised and complex needs by local authorities and the NHS in the South-West region (2005); Progress on joint commissioning (eg Eastern, London, North East, East Midlands); Audits of provision for specific LI needs (eg West Midlands (ASD) 2000; South-West (Deaf) 1999)

[49] 'Specialist provision for low incidence needs' and 'transforming special schools'

[50] Permission for this was sought from local authorities and obtained via the national advisory team.

(i)   The questionnaire would focus on the 3 main types of low incidence needs identified at the scoping stage (severe sensory/multisensory impairment; severe autistic spectrum disorders; severe behavioural, emotional and social difficulties). Additional space would be provided at the end of the questionnaire so that respondents could register issues presented by other types of need.

(ii)   Questions would be predominantly closed-ended, with a series of options based on the findings of the scoping review.

(iii)   London Authorities would receive an additional section[51], focusing on out of authority issues not covered by the main body of the questionnaire (early evidence from the ALCEO/London Challenge project indicated that a number of pupils placed out-Borough do not have 'low incidence needs' (as defined in the national Audit).

The decision was made to target the questionnaire at the 3 main statutory agencies (Education, Health, Social Services), for a number of reasons:

(i)   This would allow more uniform coverage of issues experienced across the whole of the country

(ii)   It would allow some level of regional/subregional analysis

(iii)   It would allow comparison between different agency perspectives

(iv)   Other perspectives could be more easily derived through attendance of the broader range of stakeholders at the regional/subregional focus groups

(v)   National perspectives from the key voluntary organisations, and from the independent/non-maintained sector (through NASS) had already been gathered through interviews at the scoping stage

However, the questionnaire was posted on the DfES SEN website and stakeholders were offered the chance to send in written evidence if they did not feel that their experience and perspectives were adequately covered through participation in the focus groups. A small number of written submissions was received and these were included in the overall analysis.

The views of parents and young people themselves were accessed mainly at the focus groups through the voluntary sector and Parent Partnership Officer representatives who attended[52].

---

[51] This avoided the need to send London Authorities two separate questionnaires.
[52] The research team considered that it was important to have access to the experiences and perspectives of parents and young people. For parents, the voluntary sector/Parent Partnership Officers were seen as the best means of accessing a 'representative view' (based on cumulative experience). The research team

Questionnaire structure:

The key questions covered in the questionnaire were as follows:

1) What elements of provision are considered important for children with the different kinds of low incidence needs ?

2) What are the major gaps in services, support and provision (at local/regional/ national level) ?

3) What are the key areas for development that will help address these gaps ?

The questionnaire was structured with this in mind (see Appendix 4 for the final version). For each of the 3 main types of need, respondents were asked to do the following:

(a) Elements of provision:

- look at a list of 'provision elements' (processes, types of input, experiences, professional skills/qualities, support to carers/professionals, resources) and tick if, in their view, these were important

- rate the availability of each element in their Authority area (1-5)

- list any other elements they considered to be important and rate their availability

- prioritise those elements that were currently insufficient and would make the most significant difference in meeting the needs of this group

(b) Areas for further development:

- look at a list of service/provision areas where further development might be needed (eg types of educational establishment, forms of care provision; types of health service input; other agency contributions)

- rate how much development was needed in their Authority area (1-5)

- prioritise those areas where, in their view, developments would make the most significant difference to meeting the needs of this group

---

thought long and hard about the viability of gaining young people's perspectives on services and provision. While we were aware of very valuable research and consultations carried out with more articulate young people with physical/ sensory impairments, we felt if was more difficult to obtain the views of those with more significant communication issues, within the scope and remit of this study. However, a number of examples were obtained from the focus group discussions about how young people could be more engaged in future in reviewing their own experiences of services and provision at a more local level.

- identify any other service/provision areas where they thought significant further development was needed

(c) Overall confidence in services/support/provision available:

- rate their own confidence levels in the current capacity of services/ provision in their Authority area to meet the needs of this group

- give their views on how parents/carers might respond to this question

Piloting:

The draft questionnaire was piloted at two levels: nationally, through discussion with the project steering group and with some of those interviewed during the latter period of the scoping phase; and, locally, through trials within 2 Local Authority areas in the East Midlands.

Draft questionnaires were completed by one SEN officer (Education), one Children with Disabilities team manager (Social Services) and one PCT manager. Comments were also sought from a senior speech and language therapist, and from senior specialist advisory teaching staff for each of the three main needs areas.

Comments on the format and content of the draft questionnaire were generally positive, both from national and regional respondents. Various suggestions were made for particular modifications and the final version of the questionnaire took all this feedback into account.

Process:

In order to target questionnaires to the right people in each agency, key LEA contacts were identified through the SEN Regional Partnership coordinators[53], three copies of the questionnaire were sent to each LEA contact (colour-coded for each agency), LEA officers were asked to provide names/contact details of appropriate Health/Social Services colleagues and to forward copies of the questionnaire to them for completion.

Each questionnaire had an accompanying letter, giving relevant background to the project and providing early notification of the relevant regional/subregional focus group dates. A short project summary was also attached (see Appendices 1 and 4).

Each agency was warned of the risks of subdividing the questionnaire for different individual specialists to complete 'their' section. Respondents were encouraged to give

---

[53] The decision was made to target these people directly, rather than going formally through Directors of Education, which can lead to lower response levels. SENRP coordinators were asked, where possible, to nominate officers who had both strategic and operational understanding.

their broader perceptions and were reassured that they were not required to have detailed specialist knowledge[54]. However, it was suggested that specialists might work with the respondent in producing the overall response.)

The questionnaires were sent out in the middle of May 2005, with a return date set for the end of June. Those LEAs that did not return names/contact details within a fortnight were followed up by phone/email. By the formal return date, only around 50% of questionnaire responses had been received.

Further chasing was carried out during the second half of the summer term by individual members of the research team, who were linked to particular regions[55]. A considerable amount of effort was needed to ensure the best possible return).

Response rates:

By the final deadline (middle of August), the response rate was as follows[56]:

Responses from	Number received	% of total possible
Authority areas	135	90
Education	132	88
Health	106	71
Social Services	103	69
Full sets	90	60

Return rates were broadly similar across all regions of the country and across the different types of Authority (Shire Counties, Metropolitan, Unitary etc).

Generally, responses covered all the sections in the questionnaire. However, in some of the Social Service returns, the section on BESD was not completed. Social Services questionnaires tended to be passed to the manager of the Children's Disability Team, and BESD issues were dealt with elsewhere. In most cases, the Social Services respondent was able to coordinate a full return, but, in some cases, this was not possible.

Some difficulties were encountered with Health returns, as a result of the lack of match between PCTs (primary care trusts)/Strategic Health Authorities and Local Authority areas. More than one Health response was received from some shire counties that cover several PCTs (in these cases, responses were averaged).

Education respondents' roles varied across LEAs. Some were strategic, others more operational. While this was noted, it was not possible to analyse any systematic

---

[54] In practice, some respondents did subdivide the questionnaire, and this led to issues and delays in some cases. Fortunately, most responses were eventually returned in full.
[55] Regional/subregional links were established early on in the project with a view to developing a more coherent picture of each region and ensuring continuity of contact with the relevant SENRP facilitators.
[56] A small number of further returns were received after the final deadline. Unfortunately, these could not be included in the statistical analysis.

differences in response, as specific officer responsibilities in individual Authorities were not always clear. Similar differences in levels of representation were also evident in the regional focus groups.

Most agencies provided an individual return. However, one Authority decided to produce a joint response incorporating the views of all three agencies. This was accepted but treated, for the purposes of analysis, as three separate (but identical) returns[57].

A small number of respondents decided to produce 2 separate versions of the section on sensory impairment: one for visual and one for hearing impairment. While differences were noted, responses had to be collated (averaged) so that Authority responses could be compared in the statistical analysis.

Analysis:

Data was coded and entered for computer analysis, using the SPSS package.

Responses to each section and each question were analysed overall and then by responding agency (Education/Health/Social Services) and by region. The significance of differences between agencies and regions was tested using the Kruskal Wallis test for ordinal variables.

Further details of the analysis are available on request.

c) Focus Groups:

Overall, 13 focus groups were organised, linked to the 9 new Government Office regions. To achieve some economies of scale, and in line with changing regional structure, the South Central region was paired with the South East and the North West with Greater Merseyside. Five subregional groups were held in London[58], in order that the ALCEO/London Challenge project agenda could also be addressed.

The following people were invited to each focus group:

    (i)   single representatives from each of the 3 main statutory agencies in each Local Authority area in the region/subregion: questionnaire respondents were asked to nominate these when submitting their return; those who did not send returns were followed up through e-mail/phone contact

---

[57] Consideration was given, at an early stage in the questionnaire design, to requesting a composite return across all 3 agencies. This option was rejected. While it would have been consistent with current strategic and structural directions, it was felt that processes for multiagency collaboration were not at the same stage of development across the country as a whole.

[58] North Central, North East, South East, South West and West: these linked to the London SENRP subregional structure, which is based on London's strategic health authority areas. Arrangements were made through the subregional convenors (typically LEA officers working in the area).

(ii)   Regional coordinators/facilitators/development workers for SEN, CAMHS and Valuing People

(iii)   Single representatives from the major voluntary sector organisations working with these kinds of needs (RNIB, RNID, SENSE; NAS; Young Minds; MENCAP; SCOPE): targeted through the national contacts interviewed at the scoping stage

(iv)   Single representatives from the independent/non-maintained provider sector: names were provided by the Chief Executive of NASS (the National Association of Independent Schools and Non-Maintained Special Schools)

(v)   Single representatives from the LEA-maintained school sector (special and mainstream): nominated by the SEN Regional Partnership facilitators and, in London, by the subregional convenors

(vi)   Parent Partnership Officers working in one of the Local Authority areas in the region/subregion: again nominated by the SENRP facilitator, and usually having a broader representative role in SENRP activities.

In addition, a range of other individual stakeholders was invited to specific groups, on the suggestion of the SENRP facilitators/London subregional convenors. These included:

(vii)   Senior officers from LSCs (Learning & Skills Councils)

(viii) Members of SENRP working groups (eg other special school head teachers)

A number of DfES officers and national/London project steering group members also attended, along with members of the national SEN advisory team.

Process:

The focus groups each lasted a full day[59]. Each event followed a similar pattern[60]. Following an overall introduction, the day was broken up into considering the three main needs areas in turn, with some time devoted at the end of the afternoon to other low incidence needs areas (and, in London, other out of Borough issues).

Each area began with a presentation of the main findings from the questionnaire, with comparisons made between the national picture and the responses received from the particular region/subregion. This was followed by structured small group discussion[61].

Participants were asked to do the following[62]:

_____

[59] see Appendix 5(b) for an example programme
[60] There was some variation to this in the NE regions, as a consequence of venue constraints.
[61] The composition of the groups was determined in advance to ensure a mixture of participants across different Authority areas and types of organization. In most cases, group sizes were between 5 and 10.

<ol type="i">
comment on/explore the main gaps identified by statutory agencies within the region (for that particular needs type)
identify any other gaps they considered to be equally significant
decide on the main gaps that need to be addressed
offer examples of ways in which they were currently trying to address these unmet needs/gaps in provision and promising practice that could be extended at regional/subregional level
consider what else might be done to address the key areas for development locally/regionally and what would be most helpful to support this
suggest options for the role of a 'regional centre of expertise'

Groups were facilitated by members of the research team and the SENRP coordinators, who took notes of the key points in the discussion and fed these back at the plenaries (ending each section of the day). Plenary discussions were recorded and summarised by a member of the research team, who attended in addition to the main presenter.

During the small group discussions, participants were asked to write examples of positive practice on coloured cards (different colour for each needs type). These were collated and a sample selected for follow-up. A number of these are presented as vignettes within this report, exemplifying key findings and possible ways forward for the future.

Field notes were summarised and linked to the main discussion questions. The research team then met to pool the key findings and identify any regional/subregional differences.

---

[62] See Appendix 5(c) for a copy of the group task instructions

APPENDIX 3:   LITERATURE REVIEW

NATIONAL AUDIT OF SERVICES, SUPPORT AND PROVISION FOR CHILDREN WITH LOW INCIDENCE NEEDS: A REVIEW OF THE LITERATURE

Introduction

The literature review covers the three areas of special educational need that are the focus of the DfES Low Incidence SEN Audit: sensory/multi-sensory impairment, autistic spectrum disorder and severe emotional, social and behavioural difficulties. The review does not attempt to be a comprehensive overview of the literature regarding such a broad range of needs. Its purpose was to identify key questions to be asked regarding shortfalls or gaps in local authority services and provision. The review has, therefore, focused on a number of significant contextual issues and those elements of provision that have been found to be most important in meeting the needs of children with low incidence special educational needs.

For each area of need there are separate sections for Education, Social care and Health. Whilst recognising that there will be many overlapping aspects of need and service provision, this format enables the particular issues for each service to be more clearly identified.

1. SEVERE SENSORY/MULTI-SENSORY IMPAIRMENT

Contextual issues

Incidence
The British Association of Teachers of the Deaf (BATOD estimate that there are over 25,000 children and young people with mild/moderate/profound hearing loss in England, though in most cases the loss will be mild/moderate (BATOD, 2000).   According to government statistics that there are 6,910 children of school age whose needs are sufficiently significant to warrant a statement (2,920 in primary schools, 2,300 in secondary schools and 1,690 in maintained and independent special schools). This represents 3% of all pupils with SEN at school action or with a statement of special educational need (DfES 2005). About one in a thousand children are born with a profound hearing loss (Davis et al, 1997).

The number of school-aged children with a visual impairment or with multi-sensory impairments is somewhat lower. According to government statistics there are 4,210 pupils with a visual impairment, 970 of whom are in special schools. There are 550 pupils who have multi-sensory impairment, 150 of whom pupils are in special schools. Those with a visual impairment represent 1.8% of all pupils with SEN at school action or with a statement of special educational needs, whereas children with multi-sensory impairments represent only 0.2%. Taken together they represent 2% of children with SEN (DfES, 2005).

Implications of sensory impairment
To date, much research and discussion around what are still referred to as sensory impairments have been grounded in a conceptual framework that is largely influenced by medical models of disability. However, more recent publications based on identifying the needs of children and young people and their families focus on importance of educational and social factors and equality of opportunity in removing potential 'barriers' to achievement (DfES Quality Standards, 2002; DfES, 2004). The key themes of the Every Child Matters outcomes: being healthy; being safe; enjoying and achieving; making a positive contribution and achieving economic well being, are central to the policy and practice around children who are deaf, have a visual impairment or a combination of the two.

As children learn to understand and make sense of the world around them and reflect upon it through the uses of language, any form of sensory and linguistic deprivation will, with some degree of inevitability, lead to problems in assimilating the culture of the society. The child's ability and opportunities to engage in decision making, to develop positive relationships, to develop self confidence and deal with challenge and to engage with others in a positive way will also be affected (Berger and Luckmann, 1966).

Sensory impairment impacts on every aspect of a child's development. The more severe the impairment, the greater the risk to the child's ability to develop essential social and communication skills (Anderson et al, 1984). There can be "an increasing gap between what children know, think and feel on the one hand, and what they can express, negotiate and communicate about on the other" (Wood et al, 1986). Children who fail to internalise the rules of family living may also fail to understand the conventions of social interaction in the nursery, school and a range of other social, educational and health settings. They may, moreover, seek refuge from a world that is full of contradictions and misunderstandings and fail to develop inter-personal relationships.

Ninety per cent of deaf children are born to hearing parents (RNID 2002). Early identification of sensory impairments has meant that early intervention strategies have focussed on the child's pre-school environment. The implications of this early interaction have been the subject of extensive research. This has clearly shown that the study of language development in hearing children cannot provide the answers to questions about deaf children's development, just as studies of sighted infants cannot tell us about the way a visually impaired child interprets the environment. What it does is sign post those critical areas of communication and interaction that need to be studied in the context of a sensory/multi-sensory impairment. It also highlights the importance of ensuring that children and their families receive well-informed advice and support from the start about strategies for developing communication, in addition to any practical help they might need (Bodner-Johnson, 1991; Shepherd and Gallaway, 2003).

Information for parents
Parents and carers of children and young people with a sensory impairment may feel 'disabled' by the barriers to communicating with their children and by a perceived lack of information from relevant agencies. A recent study published in Child Care Health and Development looked at the impact of written information on the stress levels of parents of visually impaired children seen in the clinic of a children's hospital. Parents of school-aged children felt that, following the diagnosis of their child's visual impairment, they had not been given enough help in understanding the implications for their child's development and education. Once the child has started school, poor communication or lack of detailed information about the educational provision was also a source of stress for parents. Where parents are better informed and confident about the provision, stress within the family can be reduced (Speedwell et al, 2003). The findings of this study typify much wider concern in the voluntary sector about the inadequacy of information available for parents (Carpenter and Herbert, 1994). The publication 'Quality Standards for Children and Young People with Sensory Impairment' highlights the need for good quality accessible information for parents from the start and throughout the child's school years (DfES, 2002; SENSE, 2003).

EDUCATION

Whilst the majority of children with hearing loss or visual impairment are educated in mainstream schools with varying levels of support, almost a fifth of deaf children are being educated in special schools (BATOD, 2003)

Communication issues
Over the past years, there has been continuing debate about the best ways of educating deaf children. Decisions on a deaf child's education have to take into account the choice of language mode (auditory-oral, total communication, sign bi-lingualism) and type of school (mainstream with or without support, unit in mainstream, specialist school). Whilst differences in opinion remain, a research report in 1998 marked a turning point in deaf education (Gregory et al 1998). Although it pre-dated the Change for Children agenda, the report focused on the educational progress and achievements of deaf children rather than the continuing debate on methods of communication. It also highlighted areas for further development and research, particularly more detailed studies of changes in teaching and curricula based on actual school practice. The authors considered that the energy put into the controversy over methods of communication has been a diversion from the content of the curriculum and to "the detriment of the education of deaf pupils" (Power et al 1998).

However, in making decisions, local authorities need to have regard for parents' and carers' preferences and, as the child grows older, his/her need to develop a positive deaf identity through either the use of

British Sign Language (BSL) as the preferred language, or as someone who primarily communicates through lip-reading, use of hearing aids and speech (RNID 2002).

Deafblind children have specific communication needs. Levels of deafness and blindness will vary, so choice of communication approach has to take account of individual circumstances and needs. Effective communication methods, such as those developed at Chailey Heritage School, remain at the heart of good practice for children with severe and complex needs (SENSE 2003).

Access and support
Since September 2002 schools and local education authorities have a requirement to ensure that disabled pupils have the same rights to access to the full curriculum and extra-curricular activities as their non-disabled peers (DDA, 1995; SENDA, 2001). Intervention and support from an early age is considered essential if children with severe sensory/multi-sensory impairment are to have access to the same opportunities as their peers. To achieve this children require support from a qualified teacher of the visually impaired/hearing impaired/multi-sensory impaired as soon as possible after diagnosis and referral, and throughout their time in school (NDCS, 2002; DfES, 2002; SENSE 2003).

Equality of access for pupils with sensory impairment also entails adaptations to the environment that take account of the developments in health and technology. A range of resources and opportunities are now available that have removed some of the barriers to the inclusion of children with sensory impairment across a range of educational provision. Such resources should also be available to support activities in the community and provide opportunities for broader social interaction with families and peers (DfES, 2002; SENSE 2003). Software to improve children's ability to read and understand text, digital hearing aids and developments in cochlear implants are, to some extent, supporting changes in policy and strategy across Children's Services and Children's Trusts and cutting across organisational boundaries (Archbold and Nikolopoulos, 2003).

An RNID report (2005) found significant variations in the type and amount of support given by specialist support services. Indicators of this variation are: the frequency of visits to children with similar needs, responsiveness to requests for support and direct support for pupils. These variations are thought to constitute a real inequality of provision. However, in the context of low incidence SEN as a whole, it is likely that support for pupils with sensory impairments is at least equal to that provided for children with other categories of need, in terms of frequency and time allocation. Pupils with sensory impairment are more likely to be supported by a teacher with a specialist qualification, while this is less likely to be the case for children with multi-sensory impairments (SENSE 2000).

Transition
Transition between phases of education and from school to adulthood can present particular difficulties for young people with sensory/multi-sensory impairment and requires careful planning and preparation (RNIB 2003; NDCS, 2005). Arrangements should be made to ensure ongoing support and access to the necessary technology and equipment. Advice from specialist Connexions Personal Advisers as well as the necessary practical help should be provided (DfES, 2002; SENSE, 2003).

Specialist provision
Historically the non-maintained sector has played a significant role in providing education for children and young people with sensory impairment through its specialist schools and colleges, some of which are residential. In respect of the total number of pupils in residential setting 19% have a sensory impairment. Among this group there are 13% with hearing impairment, 6% with visual impairment but less than 1% with multi-sensory impairment (DfES, 2004). Whilst a residential placement may be the most appropriate option for a particular child requiring highly specialist provision, or because of difficult home circumstances, it may also be the result of insufficient local specialist expertise or services, such as short-term breaks or health therapies (DfES, 2003). Given the concerns over the impact on children and young people of living away from the family and the home community, recent government guidance has emphasised the need for more local provision (DfES, 2003; DfES, 2004).

The DfES Quality Standards agenda has provided guidance for schools and local authorities on the development and monitoring of future provision (DfES, 2002; DfES, 2003). A 'National Contract for the Placement of Children in Independent and Non-Maintained Day and Residential Special Schools' has been developed by NASS, the ADSS, the LGA and the SEN Regional Partnerships and this is currently being used by 84 local authorities and 110 special schools (Pinney, 2005). Other SENRP developments have included agreements on standards of provision for sensory impairment at local and regional level (SCRIP, 2003).

SOCIAL CARE

Many children and young people with sensory impairment may not require social service involvement or support. Early Years settings and schools have demonstrated over the last decade that they have been able to remove many of the barriers to including children with a sensory impairment and have adopted a more holistic approach to meeting their needs. However, those children with severe and complex difficulties may well require intensive and long-term support (DfES 2002; SENSE 2003).

Assessment of needs
A research project looking at the mobility and independence needs of children with a visual impairment found that, for children with severe and complex needs, early support is vital, but was not consistent (VICTAR, 2005. There are few people who have the experience of working with children with severe multi-sensory impairment and who, therefore, have the confidence to provide the essential early support and assessment). Support Services around existing provision may not have the skills and capacity to carry out assessments and provide follow up services. Nor may they be able to provide the level of training that will ensure consistent good quality information and service provision across the country. There is therefore an urgent need for training in deaf, visual impairment and deaf blind awareness for all primary care workers (SENSE, 2000; DfES 2002, 2003). The project also found that mobility and independence were important factors in pupil progress and should be provided in a co-ordinated way, particularly at critical times such as transition. It also highlighted the need to work closely with parents and to take into account the views of the young persons themselves (VICTAR, 2005).

Respite Care
Children with multi-sensory impairment present particular challenges for families, and agencies. People living and working with these children will recognise characteristics such as: idiosyncratic learning styles, difficulty in establishing and developing interpersonal relationships, difficulty in anticipating future events or the results of their behaviours or actions, being labelled as "emotionally disturbed" and having a less meaningful interaction with their environment. (McInnes and Treffry, 1982). Short-break/respite care services can significantly increase a family' ability to manage the demands of caring for a child with severe disabilities. However, such services can be difficult to provide, due to the lack of skilled/experienced carers, able to communicate with the sensory-impaired child (RNID 2002; DfES 2002; SENSE 2003

Co-operation between service providers
The voluntary sector has pressed for some time for closer cooperation between agencies and for a better understanding of the needs of parents and carers. They welcome developments such as the Team Around the Child, a lead professional, a common assessment framework and an agenda for children that promotes health and well-being as well as educational progress. A Social Services Inspectorate Task Force has identified key roles for social services in relation to deaf children, and established standards in 14 areas of service (RNID, 2002).

However some organisations have expressed concerns, shared by some professionals, about the ability of new multi-professional structures to guarantee that specialists can maintain their expertise and respond to the unpredictable demands of low incidence disability (RNID, 2005).

HEALTH/MENTAL HEALTH

Children with sensory impairment, especially those who are deaf/blind or who have additional disabilities) will often have been under the care of local paediatric services since birth. However, the full extent of their

disability may not become apparent until later. Good quality assessment is therefore essential if children and their families are to be offered the support and practical help they need. A multi-professional approach encourages active partnerships between mainstream and specialist services, working together to manage disabled children's inclusion in family life, education and community services (DOH, 2000).

Incidence
Sensory impaired children are at a greater risk of developing mental health needs than their hearing peers. Research indicates that the incidence of mental health difficulties experienced by deaf people is significantly higher than for the non-deaf population, with nearly 40% of deaf people demonstrating some level of psychological difficulties (Ridgeway, 1997). An earlier study by Leigh found that the deaf college students were significantly more depressed than their hearing peers (Leigh et al, 1989). Gregory et al (1998) noted several studies into the mental health of deaf children and young people that suggest that between 40 to 50% of this population have a combination of emotional and behavioural problems, compared with 25% of the general child population (Health Advisory Service 1995).

Contributing factors
Deafness or blindness is not, of itself, a risk factor for developing mental health problems. But there are difficulties for a child and young person with a significant sensory impairment living in a society where the ability to hear and see is considered a necessity (Hindley et al, 1994). For deaf children, Gregory et al (1998) suggest that the absence of standardised tests and interview schedules for deaf young people adds problems to the validity and reliability of research in this field. These issues were explored in a more recent article on exploring the complexities of defining deaf young people's identities (Skelton and Valentine, 2003). Other studies have reported a high incidence of psychiatric disorder in blind children (Jan et al, 1977). However, since visually impaired children do not have access to visual modelling, a number of their behaviours (such as stereotypic movements and depersonalised relationships similar to those exhibited by autistic children) may incorrectly be diagnosed as pathological (Groenveld, 1990).

Availability of mental health services
Specialist mental health services for children with sensory impairment are extremely limited. There are only three psychiatric units for deaf people in the UK and only one consultant psychiatrist for deaf children (National Society for Mental Health and Deafness information).   The lack of specialist support and counselling services also affects visually impaired and deaf/blind children and young people and their families (RNIB, 2001). A major problem concerns the lack of awareness among mental health professionals about sensory impairment or the skills to communicate with deaf or multi-sensory impaired people.

Improvements to services for children and young people with visual impairment have been signalled through the publication of the Quality Standards for Children and Young People with Sensory Impairment / Visual impairment and Multi-Sensory Impairment (DfES, 2002). As far as the needs of deaf people are concerned, the concern, the government has recently published guidance, which suggests that the NHS must provide a better service for deaf people with mental health problems. Recommendations include the need for:
- Front-line NHS staff to be given deaf awareness training
- Child protection committees to review their procedures to ensure deaf children's need are being met
- Every primary care facility to have access to sign translation services
- Staff in mental health facilities to be encouraged to learn sign language
<div align="right">(DOH 2005).</div>

Multi-agency planning and co-operation

The Every Child Matters outcomes underpin the Change for Children agenda and the newly emerging structures of Children's Services departments at the Local Authority level (DfES, 2004). Inter-agency working is not new to professionals working in the area of sensory impairment. There is much evidence of good practice where teachers of the visually impaired and mobility officers are co-located in the same team or where, for instance, there are support networks around children with cochlear implants. Developing

good practice has already been identified in a number of authorities with many examples, such as in the West Midlands, of inter-authority planning and co-operative developments in strategies, materials and services (SENSE, 2005). The Social Service Inspectorate Task Force has identified departments where there is good multi-agency work, with services planned in partnership with families/carers and other agencies. They have also found that there are other areas where there is poor co-ordination between social services, other departments and agencies and little sharing of information (SSI/RNID 2002).

The government's SEN strategy contains proposals to promote effective regional planning for low incidence needs, through the regional partnerships. Professionals working in the area of sensory impairment have been critical of the lack of regional activity (with some notable exceptions) generated around sensory impairment in comparison to autism and behaviour issues (RNID, 2005). This undoubtedly reflects priorities within the local authority areas.

Providing for the needs of children and young people with significant sensory impairment requires 'joined up' solutions in a range of different settings, with support from appropriately qualified personnel who are able to carry out a collaborative assessment. People with such skills and experience exist, but not always within the same region. If children are to be educated in their local community, the specialist resources and training have to become a 'flexible, adaptable resource' (Porter et al, 2002).

REFERENCES

Anderson, E.D., Dunlea, A., Kekalis, L.S. (1984) Blind children's language: resolving some differences. *Journal of Child Language*, 11 pp 45-64

Archibold S. and Nikolopoulos, T. (2003). Multidisciplinary working practice In C. Gallaway and A. Young (Eds.) *Deafness and Education in the UK. Research Perspectives.* London: Whurr.

BATOD (2003) England Survey of the British Association of Teachers of the Deaf. BATOD website

Berger, P. L. and Luckmann, T. (1966). *The Social Construction of Reality*, Harmondsworth: Penguin.

Budner – Johnson, B. (1991). 'Family Conversation style: it's effect on the deaf child's participation', *Exceptional Children 57, 6, pp. 502 -509*

Carpenter, B. and Herbert, E. (1994). School based Support. In P. Mittler and H. Mittler (Eds.) *Innovations in Family Support for People with Learning Disabilities*. Chorley: Lisleux Hall.

Davis, A et al (1997) *A critical review of the role of neonatal screening in the detection of hearing impairment*: Nottingham: Institute of Hearing Research

DFEE, (1998). Power, S., Gregory, S. and Thoutenhoof, d. The Educational Achievements of Deaf Children. *Research Report RR 65*.

DfES (2001) SEN Code of Practice. London: The Stationery Office

DfES (2002*) Quality Standards for Children and Young People with Sensory Impairment.* London: The Stationery Office

DfES (2002) *Quality Standards for Children and Young People with Visual Impairment.* LEA/0138. London: The Stationery Office

DfES (2002) *Quality Standards in Education Support Services for Children and Young People who are Deafblind/Multi-Sensory Impaired.* London: The Stationery Office

DfES (2003) *Together from the Start*. LEA/0067. London: The Stationery Office

DfES (2003) *An Investigation into the funding of SEN provision in schools and education elsewhere.* London: The Stationery Office

DfES (2004) *Every Child Matters: Change for Children*. London: TSO

DfES (2004) *Removing the Barriers to Achievement: The Government's Strategy for SEN.* London: The Stationery Office

DfES (2004) *The National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs.* London: The Stationery Office

DfES (2005) *National Statistics: First Release, special educational needs in England.* London: The Stationery Office

Department of Health (2000) *Assessing Children in Need and their Families: Good Practice Guidance.* London: Department of Health

Department of Health (2005) *Mental Health and Deafness: Towards Equity and Access. Best Practice Guidance*. London: Department of Health

Gregory, S., Knight, P., McCracken, W., Powers, S. and Watson, L. (Eds.) (1998). *Issues in Deaf Education*. London: David Fulton.

Groenveld, M. (1990) The dilemma of assessing the visually impaired child. *Developmental Medicine and Child Neurology*, 32, pp 1105-1109

Health Advisory Service (1995) *Thematic Review of \Services to Deaf People*. London: Department of Health (unpublished)

Hindley, P Hill, P., McGuigan, S., Kitson, N. (1994) *Psychiatric Disorder in Deaf and Hearing Impaired Children and young People: a prevalence study*. NDCS website: www.ndcs.org.uk

Leigh, I. Robbins,S.J., Welkowitz, J. Bond. R.N. (1989) Towards a greater understanding of depression in deaf individuals, *American Annals of the Deaf,*

McInnes, J., Treffry, I. (1982). *Deaf – Blind Infants and Children. A Development Guide*

Pinney, A. (2005) *Disabled children in residential placements.* Research project on behalf of the DfES.

Porter, J., Lacey, P. et al (2002). *The Role of Special School: A Review of the Literature.* DfES

NDCS (National Deaf Children's Society) (2005) *Quality Standards and Good Practice Guidelines: Transition from Child to Adult Services*. London: NDCS/ MICHAS

Ridgeway, S. (1997) Psychological *Health and Well being in a Deaf Population* (unpublished). Manchester: Manchester University

RNIB (Royal National Institute for the Blind) (2001) *Blind and Partially-Sighted Children in Britain*: the RNIB survey, Vol 2. RNIB

RNIB (Royal national Institute for the Blind) (2003) *West Midlands Social Inclusion Project*. RNIB and University of Birmingham

RNID (2002) *Deaf Children; Positive Practice Standards in Social Services*. RNID/SSI

RNID (Royal National Institute for the Deaf, (2005). *At the heart of inclusion: the role of specialist support for deaf pupils.* RNID

SCRIP/SERSEN, SouthEast/South Central Regional Inclusion Partnership (2003) *Developing Partnerships between Local Education Authorities and Independent and Non-Maintained Special Schools.*

SCRIP, South Central Regional Inclusion Partnership (2003) *Quality Standards in Education Services for Children and Young People with Sensory Impairment.*

SENSE (2000) *Examples of good practice in local authorities*. SENSE website: www.sense.org.uk

SENSE (2003) *Quality Standards in Education Support Services for Children and Young People who are Deafblind/Multi-Sensory Impaired.* London: SENSE

Shepherd, M. and Gallaway, C. (2003). Interaction with a deaf child: the contributions made by mother, father and sister. In Gallaway, C. and Young, A (Eds.) *Deafness and Education in the UK*. London: Whurr.

Skelton, T.L. and Valentine, G., (2003) "It feels like being deaf is normal", *The Canadian Geographer*, 47 (4), pp451-446. Blackwell.

Social Services Inspectorate (2002) *Deaf Children: Positive Practice Standards in Social Services.* SSI/RNID

Speedwell, L., Stanton, F. and Nischall, K. K. (2003). Informing Parents of Visually Impaired Children. In *Child Care, Health and Development 29, **3**, pp. 219 – 224*

Teacher Training Agency (1999) *The National SEN Specialist Standards.* London TTA

VICTAR: Visual Impairment Centre for Teaching and Research (2005) *Steps to Independence: the mobility needs of children with a visual impairment.* Birmingham: Birmingham University

Wood, D. J., Wood, H., Griffiths, A. and Howarth, I. (1986). *Teaching and Talking with Deaf Children*, London: John Wiley.

2. SEVERE AUTISTIC SPECTRUM DISORDERS (ASD)

Contextual Issues

Autism is a complex disability that presents many challenges to education, social and health servicesin terms of understanding, provision and services.

Incidence
It is almost impossible to know with any degree of accuracy how many children and young people suffer from the disorder, mainly because the term covers a wider range of learning and communication difficulties. There is no agreed medical test that can determine whether or not a person has autism, and professionals differ in the way they apply what recognised criteria there are.

Various studies have estimated that the prevalence may be between 20 and 35 per 10,000 in the population (Wing and Gould, 1979; Ehlers and Gilberg, 1993; Arvidson et al, 1997). There is a general belief that numbers are increasing and some recent studies suggest that there may be between 60 and 91 people in every 10,000 (MRC, 2002; NAS, 2005), although this could be related to changes in referral patterns and in diagnostic criteria (MRC, 2001). Government statistics indicate that there are 26,730 pupils with a statement for ASD: 11,100 in primary schools, 5,910 in secondary schools and 9,710 in maintained and independent special schools. This represents 11.5% of all pupils with SEN at school action or with a statement (DfES, 2005).

Impact on learning and communication
All children and young people on the autistic spectrum have a triad of impairments in common: they all have difficulty to some degree with social interaction, communication and flexible thinking. Autism can affect children with profound and/or multiple learning difficulties as well as those with average/above average abilities. This triad of impairment can lead to differences in learning, thinking and perception, which, in many instances, may result in behaviour, which is difficult to manage (NAS, 2005).

Identification and assessment
Early identification is thought to be important in order to provide parents with appropriate advice and support. But it is not easy at the early stage to distinguish between what might be a child's reactions to family circumstances and what might be a genuine developmental disorder. There are no uniform methods of early identification of ASD. The routine use of CHAT (Checklist for Autism in Toddlers) by health visitors is being introduced in some areas at the 18-month/2 year developmental check (West Midlands SEN Regional Partnership 2001).

Support for families
The importance of appropriate provision and support from formal agencies to families with children who have ASD is emphasised throughout the literature, particularly for those with children who have severe forms of the disorder. However these can be the children whose needs are among the most difficult to meet within generic local provision, and who therefore may require expensive provision, sometimes in a residential setting. Government guidance continues to emphasise the need for good communication networks between the LEA, Health and Social Services departments to ensure a three-way flow of information regarding ASD policy and practice (DfES, 2002).

EDUCATION

General considerations
Early intervention at the pre-school and nursery stage, with clearly targeted programmes to develop children's social and communication skills, is thought to help prevent the escalation of problems within school and the family and to improve the children's chances developing optimum independence (DfES/DOH, 2002).

Appropriate and effective education provision is a major source of support. Parental satisfaction with the child's school placement has been shown to reduce family stress (Carpenter & Herbert, 1994; Oberheim,

1996). This satisfaction is of course dependent on the quality of the provision the child receives. Many children and young people with ASD can be successfully taught alongside their peers in mainstream schools, with appropriate levels of support (Jordan and Powell 1997; DfES/DOH, 2002). However, it is generally acknowledged that many children with ASD, due to their problems with social interaction, receptive and expressive communication, and their need for routine and sameness, are likely to need differentiated forms of educational provision (AHTACA, 2000).

For children and young people with more severe impairment, long-term differentiated and even specialist support is needed, such as that which is available within designated schools, resourced to provide for pupils with ASD ((DfES/DOH, 2002; Jones, 2002). Some children with the most severe impairment may need the highly specialised provision offered by special schools. (Jordan 2001).

Specific programmes and interventions

Within both mainstream and special schools, a range of specialist programmes and educational interventions is currently provided in the UK for children with ASD. The following approaches are widely used.

Language interventions
Language and communication interventions are vitally important in ASD. Language development needs regular support. Research suggests that virtually all children can learn to use some form of symbolic communication system to express needs, wants and preferences if communication interventions are systematically undertaken. Effective functional communication systems include those used within the PECS and TEACCH models (Mastergeorge, Rogers, Corbett & Solomon, 2003).

Picture Exchange Communication System (PECS)
PECS was developed in the USA by Bondy and Frost to address the area of communication skills in ASD. It was introduced to the UK in 1997 and is now widely used. PECS teaches children to exchange symbols or pictures for the desired object or activity (Bondy & Frost, 1994). Independent studies supporting the approach are beginning to appear (Webb, 2000).

Treatment and Education of Autistic and Communication Handicapped Children (TEACCH)
This approach was developed in the USA in the 1970s, and is now probably the most well-known and commonly used intervention in the UK. It is based on the conceptualisation that children with ASD are visual learners, and has developed a model of 'structured teaching' to teach to these strengths. TEACCH does not aim to 'cure' or 'remove' autism - it considers ASD to be a lifelong condition (Schopler, Mesibov & Hearsey, 1995). Research supports the benefits of the use of structure and visual supports to people with ASD. Where the approach is used within the home as well as at school, positive results have been reported for both children and families (Howley, Preece & Arnold, 2001). However, apart from a few small-scale studies in the USA and Europe, there is little published evidence on its effectiveness and outcomes, and further research remains needed.

Social Stories
This approach, developed by Gray, uses individualised stories to present appropriate social behaviour, and teach social rules, in a visual, autism-friendly way (Gray & Garard, 1993). The technique is widely recommended and is used in schools across the UK. The few small studies undertaken so far have been promising (Norris & Dattilo, 1999).

Makaton communication system
Makaton is a signing system developed in the UK in 1972, which is used internationally for people with communication difficulties, primarily those with learning disabilities. In work with children with ASD Makaton is primarily used alongside speech to provide an extra cue, rather than being taught as an alternative communication system to replace speech (Walker, 1980). Though widely used, particularly in generic 'learning disability' settings, concerns exist with regard to the efficacy of signing for children (Attwood, Frith & Hermelin, 1988); moreover the use of symbols and pictures seems easier and they are more widely understood in general society.

Music Interaction Therapy
This approach was developed at Sutherland House School, Nottingham. The child's parent, or key worker, works with the child and a musician plays an instrument to support and facilitate the interaction between the two (Prevezer, 2000). There is some research evidence to support the approach (Wimpory, Chadwick & Nash, 1995), though further research is needed.

Other considerations

The management of change and transition
Children and young people with ASD have particular difficulty in coping with change. They need help in adjusting to different educational settings and to new members of staff. Careful and thorough planning and support is therefore essential for transition from one phase of education, or from one setting, to another. This is especially important when planning transition from school to college, or when transferring from child to adult services. The role of the Connexions Service in assisting in transition post-16 has been highlighted (DfES/DOH, 2002).

Colleges are thought to be less well prepared to make provision for students with autism than in their provision for students with other special needs. Research into the needs of students with ASD has found that they need to be better prepared for what they can expect from college, and staff need to have a better understanding about what to expect from the students (Coates and James, 1995).

Home-based programmes

Some approaches involve such intensive daily intervention that they may only be able to be provided within the home, though some have elements that can also be offered in school. A significant number of families in the UK choose to follow such programmes during their child's early years.

Applied Behavioural Analysis
This programme uses behavioural methods to teach skills and reduce inappropriate behaviours. The approach has received great interest and attention, particularly due to the reported outcomes of the approach: Lovaas reported that 47% of the 19 children in his study who had followed the programme for 40 hrs per week for 2 years were 'indistinguishable from their normal peers' (Lovaas, 1987). Many children in the UK are now following this approach, usually taught one-to-one at home, though there are schools which make use of the approach. ABA has attracted criticism both in terms of the research design, methods and reporting (Mesibov, 1993; Shea, 2004) and regarding the ethics of the approach (Dawson, 2004).

Daily Life Therapy (DLT)
This approach was developed in Japan in the 1960s and focuses on building physical strength, stabilising emotion and normalising intellectual interests (Kitahara, 1984; Quill, Gurry & Larkin, 1989). A school was opened in Boston USA, in 1987 – in 1998, 26 of the 100 pupils were from the UK. Two schools have been set up in the UK following DLT principles. There is research evidence to support the importance and benefits of physical exercise in reducing stress and challenging behaviour (Gabler-Halle, Halle & Chung, 1993). Other aspects of the approach cause more concern, including the lack of individual differentiation, and the curriculum's relevance to UK pupils (Shea, 2004).

Intensive Interaction
This programme is based upon early parent-child interactions. Key features include acting as if the individual intends to communicate, and following their lead. It is intended to take place within the classroom, in short daily interactions (Nind & Hewett, 1994). Positive results have been reported by the creators of the approach (Nind, 1999).

Option Approach (Son Rise)
This approach was developed by the Kaufmans in the USA. They worked with their son, using this approach, based on intensive one-to-one interaction, from the age of 17 months, and report that he

recovered from autism (Kaufman, 1994). They now run the Option Institute in Massachusetts, which a number of parents from the UK have attended for 1-2 week assessment. An Option Centre has now opened in London. However, although the Kaufmans maintain that it seems possible to achieve a 'cure' from autism using their approach, no systematic or independent research has been carried out, and evidence is limited to reports from families and the Option team.

SOCIAL CARE

Direct support from social care providers is usually needed by families with more challenging children. An assessment of 'intellectual abilities' is often required to access both Learning Disability (Social Services/Health) and Mental Health Services. Some professionals and parents feel that children and young people with Asperger's syndrome or high functioning autism and challenging behaviour are disadvantaged because they do not meet the criteria for support (West Midlands Regional Partnership, 2001).

Short breaks (respite care)
The provision of short breaks has been identified as a key support need for families with children with ASD (Beresford, 1994; Factor, Perry & Freeman, 1990, Chan & Sigafoos, 2001). Though some researchers and practitioners consider these services stigmatising to the disabled child (Cocks, 2000), it is generally acknowledged that successful and appropriate short breaks can prevent family breakdown and children being placed out of the home (Abelson, 1999; Boyd, 2002).

There are insufficient short break services available to families with children with ASD in the UK. Barson (1998) surveying residential short breaks services in Wales, found that only 7% of families were able to access such services; and Brady (1998) states that 55% of families of children with ASD consider lack of short breaks services to be a problem. Families with children with ASD often spend years on waiting lists without ever eventually receiving a service (Sargent, 1995; Barson, 1996). Almost a third of all children on waiting lists for short breaks in the UK have ASD (Tarleton and Macauley, 2003). More able children with ASD, such as those with Asperger's syndrome, may be viewed as intellectually 'too able' to meet eligibility criteria (Oberheim, 1996).

Those individuals with ASD who are able to access to the scarce residential services are often subsequently excluded from them as a result of the impact of their behaviours on other service-users (Van Bourgondien and Elgar, 1990). Where children with ASD are placed in 'Family Link' placements, these links break down more frequently than those of children with other disabilities (Barson, 1998).

Where short breaks are available, these tend to be within the context of generic services for 'disabled children'. Many parents find these services inadequate or inappropriate. Care staff are often considered unskilled and lacking an understanding of ASD (Barson 1998; Forrest, 1994; Hand, 1994). Further problems include service-user mix, activities, situational factors (e.g. security, space, safety, noise), staffing levels and training (Barson, 1998; Oberheim, 1996; Sargent, 1995).

A way forward may be the development of ASD-specific short breaks services, using ASD-specific interventions consistent with those used in educational settings (Preece, 2003). Some provision (both residential and family-based) has been established in some parts of the country. Initial research carried has indicated parental satisfaction to be high, and the ASD-focus to be valued (Preece, 2000).

Alternative forms of service provision
Recent research has identified a need for alternative forms of support. Alternative models of service provision to support young people and their families have been developed in some areas. These include 'sessional' or befriending schemes; holiday play schemes; and the provision of short breaks in the child's own home. However such developments have been largely unevaluated, and those studies that have been carried out have not had an ASD-specific focus (Preece, 2000).

Longer-term care
If families cannot continue to care for their child with autism, but the child's educational needs are being met within the local authority, the provision of specialist long-term care (either in a specialist fostering or

residential setting) can prevent out-of-authority placements. Some local authorities (e.g. Bolton, Northamptonshire) have developed such provision. The potential benefits include:
- the child remaining close to family so positive contact can be maintained
- transition to adult services can be carried out more effectively if child is in-authority
- continuity of education can be maintained, thus reducing change for the child
- potential financial savings to the authority.

However, though these services are inspected by CSC, these methods of service provision have yet to receive formal research evaluation.

HEALTH/MENTAL HEALTH PROVISION

There has been considerable recent research concerning the aetiology, assessment and treatment of autistic spectrum disorders. Much of this research has implications for clinical practice, particularly in the areas of psychology and pharmacotherapy.

Psychological interventions
Parent training is an important intervention with regard to maintaining family stability. Positive outcomes have been identified with regard to coping skills training (Ergüner-Tekinalp. & Akkök, 2004), to psycho-educational training such as TEACCH parent-training, and the National Autistic Society EarlyBird Scheme (Bristol, Gallagher & Holt, 1993; Shields, 2001). Parent management training has also been found to be effective in helping families manage their children's behaviour (Sofronoff, Leslie & Brown, 2004).

Medication
Medication plays a limited role in the treatment of autism as there is no pharmacological remedy for the disorder (Batshaw et al, 1992). However, new drug treatments are being developed to manage some of the problems associated with ASD, such as mood instability and sleep disturbances. Though results are favourable, problems still exist, due to the wide spectrum of ASD, and the fact that not all children and adolescents with ASD respond favourably to particular drugs. Additional research is needed to help better match medication to particular children and particular target symptoms (des Portes, Hagerman & Hendren, 2003).

Behaviour management
Positive methods of managing behaviours, based upon an understanding of the underlying difficulties of ASD, are needed across all settings. Essential components of any model include:
- understanding the potential causes of 'challenging behaviour' in ASD
- effective tools to assess and analyse the observed behaviours and their underlying causes
- long-term positive approaches to behaviour management, based on teaching and reinforcing appropriate behaviours and providing 'autism-friendly' environmental conditions
- least-restrictive methods of ensuring the safety of the children with ASD, staff and others.

The STAR model (Zarkowska & Clements) is a useful functional analysis tool, developed specifically for people with challenging behaviours and developmental disabilities. There are a number of commercially marketed models of behavioural intervention, including *Strategies for Crisis Intervention and Prevention (Pro-act SCIP-r UK), Studio Three* and *Team Teach* (not to be confused with TEACCH), all of which are in use in different settings across the UK. Though the underlying philosophy of all these approaches is similar, the physical interventions differ. It is important that all staff working with a child and his/her family are consistent in the approach they use.

Strategic planning
The recent government guidance on best practice for pupils with ASD emphasises the need for clear links to be established between key strategic policies and plans for ASD provision within the authority. The Good Practice Guidance states that is essential that local authority agencies have effective systems for communicating with one another. It reports that there are encouraging examples of regular meetings between planners or case-workers to plan services for individual children and families (DfES/DOH, 2002).

REFERENCES

Abelson, A.G. (1999) Respite care needs of families with children with developmental disabilities, *Focus on Autism and Other Developmental Disabilities,* **14**, 96-109.

AHTACA (2000) *The Special Curricular Needs of Children with Autistic Spectrum Disorders.* London AHTACA.

Arvidson, T. et al (1997) 'Autism in 3-6 year olds in a suburb of Gotenberg, Sweden'. *Autism* **2**, 163-174

Attwood, A., Frith, U. & Hermelin, B. (1988) The understanding and use of interpersonal gestures by autistic and Down's syndrome children, *Journal of Autism and Developmental Disorders,* **18**, 241-257.

Barson, C. (1998) *Autism: Supporting the Family. A report on the short-term care needs of children with autism in Wales*. London: National Autistic Society.

Batshaw, M.L and Perret, Y. (1992) *Children's Disabilities: A Medical Primer.* London: Paul Brookes publishing Co

Beresford, B. (1994) *Positively Parents: Caring for a Severely Disabled Child*. London: HMSO.

Bondy, A.S. & Frost, L.A. (1994) The Delaware autistic program. In S.L. Harris & J.S. Handleman (Eds) *Preschool Education Programs for Children with Autism*. Austin, TX: Pro-Ed.

Boyd, B.A. (2002) Examining the relationship between stress and lack of social support in mothers of children with autism, *Focus on Autism and Other Developmental Disabilities*, *17*, 208-215.

Brady, P. (1998) *Shaping Family Support: a study of specialist community based support for families of people with autism spectrum disorders*. Nottingham: National Autistic Society.

Bristol, M.M., Gallagher, J.J. & Holt, K.D. (1993) Maternal depressive symptoms in autism: response to psycho educational intervention, *Rehabilitation Psychology,* **38**, 3-10.

Carpenter, B. & Herbert, E. (1994) School based support. In P. Mittler & H. Mittler (Eds) *Innovations in Family Support for People with Learning Disabilities*. Chorley: Lisieux Hall.

Chan, J.B. & Sigafoos, J. (2001) Does respite care reduce parental stress in families with developmentally disabled children, *Child and Youth Care Forum*, *30*, 253-263.

Cocks, A. (2000) Respite care for disabled children: micro and macro reflections *Disability and Society*, **15**, 507-519.

Dawson, M. (2004) The misbehaviour of behaviourists: ethical challenges to the autism-ABA industry, http://www.sentex.net/~nexus23/naa_aba.html

DfES/ Department of Health (2002) *Autistic Spectrum Disorders: Good Practice Guidance.* London: DfES

DfES (2005) *National Statistics: First Release, special educational needs in England.* London: DfES

des Portes, V., Hagerman, R.J. & Hendren, R.L. (2003) Pharmacotherapy. In S.Ozonoff, S.J. Rogers, & R.L. Hendren (Eds)(2003) *Autism Spectrum Disorders: a research review for practitioners*. Arlington, VA: American Psychiatric Publishing, Inc.

Ehlers, S. and Gilberg, C. (1993) The epidemiology of Aspberger Syndrome; a total population study. *Journal of Child Psychology and Psychiatry* 34 (8) pp 1327-1350

Ergüner-Tekinalp, B. & Akkök, F. (2004) The effects of a coping skills training program on the coping skills, hopelessness and stress levels of mothers with children with autism, *International Journal for the Advancement of Counselling***, 26**, 257-269.

Factor, D.C., Perry, A. & Freeman, N. (1990) Stress, social support and respite care use in families with autistic children, *Journal of Autism and Developmental Disorders,* **20**, 139-145.

Forrest, A. (1994) *Autism: the Invisible Disability. The implications of current legislation for meeting the needs of children with autism*. London: National Autistic Society.

Gabler-Halle, J.W., Halle, D. & Chung, Y.B. (1993) The effects of aerobic exercise on psychological and behavioural variables of individuals with developmental disabilities: a critical review, *Research in Developmental Disabilities*, **14**, 359-386.

Gray, C. & Garard, J. (1993) Social stories: improving social responses of students with autism with accurate social information, *Focus on Autistic Behaviour***, 8**, 1-10.

Hand, E. (1994) *The Image of Support: how mothers of autistic children see the caring agencies*. London: Cicely Northcote Trust.

Howley, M., Preece, D. & Arnold, T. (2001) Multidisciplinary use of 'structured teaching' to promote consistency of approach for children with autistic spectrum disorder, *Educational and Child Psychology*, **18**, 41-52.

Jones, G. (2002) *Educational Provision for Children with Autism and Asperger Syndrome: Meeting their Needs.* London: David Fulton.

Jordan, R. and Powell, S. (1997) *Autism and Learning: A guide to good practice.* London: David Fulton Publishers

Kaufman, B.N. (1994) *Son Rise: the miracle continues.* California: Kramer.

Kitahara, K. (1984) *Daily Life Therapy: a method of educating autistic children, Vols 1-3.* Boston MA: Nimrod.

Lovaas, O.I. (1987) Behavioural treatment and normal intellectual and educational functioning in autistic children, *Journal of Consulting and Clinical Psychology*, **55,** 3-9

Mastergeorge, A.M., Rogers, S.J., Corbett, B.A. & Solomon, M. (2003) Non-medical interventions for Autism Spectrum Disorders. In S. Ozonoff, S.J. Rogers, & R.L.Hendren (Eds)(2003) *Autism Spectrum Disorders: a research review for practitioners.* Arlington, VA: American Psychiatric Publishing, Inc.

Mesibov, G.B. (1993) Treatment outcome is encouraging: comments on McEachin et al, *American Journal of Mental Retardation*, **97**, 379-80

Medical Research Council (2001) *Review of Autism Epidemiology and Causes.* MRC/DOH

National Autistic Society (NAS) (2005): www: autism.org.uk

Nind, M. (1999) Intensive interaction and autism: a useful approach? *British Journal of Special Education,* **26**, 96-102.

Nind, M. & Hewett, D. (1994) *Access to Communication.* London: David Fulton.

Norris, C. & Dattilo, J. (1999) Evaluating effects of a social story intervention on a young girl with autism, *Focus on Autism and Other Developmental Disabilities*, **14**, 180-186.

Oberheim, D. (1996) *The Support Needs of Adults and Children with Autism and their Carers in Kent.* Gillingham: Kent Autistic Trust.

Preece, D. (2000) An investigation into parental satisfaction with a short-term care service for children with an autistic spectrum disorder, *Good Autism Practice*, **1**, 42-56.

Preece, D. (2003) Providing an 'autism-friendly' service for children with an autistic spectrum disorder in a short-term (respite) care setting, *Journal of Integrated Care*, **11**, 39-44.

Prevezer, W. (2000) Musical interaction and children with autism. In S. Powell (Ed) *Helping Children with Autism to Learn.* London: David Fulton.

Quill, K., Gurry, S. & Larkin, A. (1989) Daily Life Therapy: a Japanese model for educating children with autism, *Journal of Autism and Developmental Disorders,* **19**, 625-634.

Sargent, J.A. (1995) *The Future of Respite Care Resources for Children with Autism in North East Essex.* Colchester: Essex County Council.

Schopler, E., Mesibov, G.B. & Hearsey, K. (1995) Structured teaching in the TEACCH approach. In E. Schopler & G.B. Mesibov (Eds) *Learning and Cognition in Autism.* New York: Plenum.

Shea, V. (2004) A perspective on the research literature related to early intensive behavioural intervention (Lovaas) for young children with autism. *Autism: the International Journal of Research and Practice*, **8**, 349-368.

Shields, J. (2001) The NAS EarlyBird programme: partnership with parents in early intervention, *Autism: the International Journal of Research and Practice*, **5**, 49-56.

Sofronoff, K., Leslie, A. & Brown, W. (2004) Parent management training and Asperger Syndrome: a randomized controlled trial to evaluate a parent based intervention, *Autism: the International Journal of Research and Practice*, **8**, 301-318.

Tarleton, B. & Macaulay, F. (2002) *Better for the Break? Short break services for children and teenagers with autistic spectrum disorders and their families.* York: Shared Care Network.

Van Bourgondien, M.E. & Elgar, S. (1990) The relationship between existing residential services and the needs of autistic adults, *Journal of Autism and Developmental Disorders*, **20**, 299-308.

Walker, M. (1980) *The Makaton Vocabulary (Revised).* Camberley: The Makaton Vocabulary Development Project.

Webb, T. (2000) Can children with autism be taught to communicate using PECS, *Good Autism Practice*, **1**, 29-41

West Midlands SEN Regional Partnership (English, A. and Essex, J.) (2001) *Report on Autistic Spectrum Disorders.* West Midlands

Wimpory, D., Chadwick, P. & Nash, S. (1995) Musical interaction therapy for children with autism: an illustrative case study with a two-year follow-up, *Journal of Autism and Developmental Disorders*, **25**, 541-552.

Wing, L. and Gould, J. (1979) Severe Impairments of social interaction associated with abnormalities in children: epidemiology and classification. *Journal Of Autism and Developmental Disorders,* 9(1) 11-29

Zarkowska, E. & Clements, J. (1989) *Problem Behaviour and People with Severe Learning Difficulties: the STAR Approach.* London: Chapman Hall

3. SEVERE BEHAVIOURAL, EMOTIONAL AND SOCIAL DIFFICULTIES (BESD)

Contextual Issues

Defining BESD
The literature highlights the difficulty of agreeing terminology in this area. Kauffman, cited in John Visser's comprehensive survey of the field (Visser, 2003), states that 'the problem of definition is made all the more difficult by differences in conceptual models, differing purposes of definition, the complexities of measuring emotions and behaviour, the range and variability of normal' (Kauffman, 2001).

In Circular 9/94, the Department for Education gave a detailed and extended definition of EBD. Social, psychological and sometimes biological factors, or interactions between these three strands, are seen as main causes of young people's difficulties (DfE 1994b). Subsequent government documents and papers have continued to attempt to redefine the characteristics of emotional and behavioural difficulties, encompassing those that include disruptive, anti-social and aggressive problems, peer relationships, somatic, emotional and related disorders and mental health problems (Circular 9/94, Code of Practice, DfE 1994; Audit Commission, 1999; DOH 2000).

Behaviour difficulties form part of a continuum, with no clear distinctions between types and levels of difficulty. In times past, attempts were made to distinguish between young people whose behaviour was linked to disaffection and those who were 'disturbed', but this was always problematical. Various diagnostic and assessment tools are sometimes used to identify particular types and levels of difficulty. Some have been found to be useful (Sigafoos et al, 1997; Bennathan, 1998; Berridge et al, 2002). But many are criticised for focusing too heavily on 'within-child factors' and their failure to take account of the social construction of much of the 'challenging' or disturbing behaviour (Visser, 2003). The difficulty in defining the population can be exacerbated by the often differing perspectives between education, health and social services as to the causes of the distressed, disturbing or challenging behaviour, and therefore as to what should be the most appropriate response.

Incidence
The problem associated with defining and assessing behavioural, emotional and social difficulties means that the numbers of pupils with serious BESD/challenging behaviour can only be estimated (Visser, 2003). Government statistics on SEN indicate that there are 32,290 pupils with a statement for EBD in maintained and independent schools in England: 8,250 in primary schools, 11,790 in secondary schools and 12,250 in maintained and independent special schools (DfES, 2005). This represents 13.9% of all pupils at with SEN at Action Plus or with a statement. It is estimated that there are ten to twelve times more boys than girls in English EBD schools, and over three times as many boys as girls in PRUs (Cole et al, 1998).

Given these numbers, it is clear that BESD is a high (not a low) incidence phenomenon. Nevertheless, some children and young people suffer extreme levels of emotional, social and mental stress, which call for higher levels of support. The fact that the highest percentage of young people who are placed in residential schools are there for reasons of BESD suggests that this is the area for which local authorities find most difficult to provide (Pinney, 2005).

Vulnerable groups
Some children and young people are especially vulnerable and as a result may develop severe BESD. Looked after children are five times more likely to develop a mental health problem than children in private households (Meltzer et al, 2002). Also at risk are children and young people who are victims of sexual abuse, emotional abuse, violence and neglect, as well as those who are involved in alcohol or substance abuse, or who suffer from a range of anxiety-related problems (Graham and Hughes, 1995). Other vulnerable groups include young carers (Carers National Association, 1996), refugees and asylum seekers (Young Minds, 1995; Audit Commission, 2000.) and children with learning and sensory disabilities.

EDUCATION

Difficulties in agreeing definitions that adequately describe the many and varied manifestations of BESD result in varying practices and standards across different schools and LEAs in identifying, assessing and providing for children and young people considered to present significant BESD (Galloway et al, 1994; Kelly and Gray, 2000).

The challenge of inclusion
Circular 1/98 requires LEAs to make comprehensive, co-ordinated provision for pupils with EBD. However, BESD is the 'special need' that mainstream schools (as well as LEAs) are most likely to find difficult to accommodate, especially where the young person's behaviour is violent or highly disruptive (Millward and Robson, 1999; Croll, 2001). Nevertheless, schools demonstrating effective, consistent practice and an inclusive ethos can be successful in providing for even the most vulnerable and challenging pupils (Lindsey, 1997; Munn et al, 2000, Visser et al, 2002).

Leadership and management
Commitment and support for the head and staff from school governors have been found to be a key factors in schools' ability to retain and support young people with challenging behaviour (Galvin and Costa, 1994; Cole et al, 1998). Schools that are successful in supporting pupils with special needs and BESD have usually established a consultative, co-operative style of leadership, where staff are committed, caring and are prepared to listen (Miller, 1996; Cole et al. 1998; Ofsted, 1995).

Curriculum
Pupils with challenging behaviour need a stimulating and accessible curriculum that can be adapted to meet individual needs and interests. Where pupils are in specialist provision, they benefit from a curriculum that works towards their re-inclusion into mainstream wherever possible (Ofsted, 1999a; QCA, 2001; DfES, 2002). Recent developments in the 14-19 curriculum encourage schools to develop a broader range of opportunities for those who are more likely to respond well to a vocational programme (Ofsted, 1999a; Bell, 2005). This is in line with the Children's Act (2004), which requires a curriculum that addresses the needs of the 'whole' child.

Teaching and learning
Successful schools have skilled, confident and competent teachers, with excellent class management (Bull, 1995; Ofsted: 1999, 2001, 2002, 2003). Teaching and learning is geared to the individual needs of pupils, ensuring achievable steps and the recognition of achievement (Ayers et al, 2000). Such schools make efficient use of additional assistance in the classroom (Lacey, 2001). They are also likely to provide additional specialised behavioural and cognitive programmes which aim to help young people develop social competence and emotional maturity, adjust to school expectations and routines, acquire the skills of positive interaction with peers and adults (DfES, 2002).

Pastoral support
Good pastoral support arrangements, well-targeted pastoral support plans agreed with pupils and parents and effective transition arrangements increase the likelihood that the great majority of problems in behaviour and relationships can be successfully managed in school (DfEE, 1999; Ofsted, 1999a).

Mentoring
Mentoring is increasingly offered in schools to a wide range of children and young people. When the mentoring relationship succeeds both mentors and young people find it a positive experience, and many are able to sustain the relationship over a period of time (St James-Roberts et al, 2001). But there is a lack of empirical evidence to show that mentoring changes young people's behaviour (Tarling et al, 2001; Smith 2002).

Nurture groups
Nurture groups, where up to 12 primary-aged children are taught for a specified period of time by 2 adults, have been successful in changing young children's behaviour and in developing their social skills ((Bennathan, 1998, 2003). About half of all councils are currently running, or plan to run them. Some

nurture groups in secondary schools have recently been established in Staffordshire, Thurrock and Cambridge (Smith, 2002)

Training
Staff in both mainstream and specialist EBD schools need on-going support and training to develop their understanding and skills in the management of behaviour (DfEE, 1997; Ofsted, 1999; Ayers et al, 2000). A number of training programmes designed to develop whole school approaches, through staff training and consistent management practice, have been found to reduce the incidence of disruptive behaviour and help avoid exclusions (Galvin and Costa, 1994; Birmingham City Council, 2001).

Partnership with parents and other agencies
Effective provision encourages a partnership with parents, however problematic this may be in individual cases. Parents value direct help and guidance in understanding and managing their children's behaviour (Ofsted, 1999a, 2001). Schools increasingly work in collaboration with other agencies. Multi-agency support is essential for the most complex cases with priority given to increasing the level of social service and CAMHS involvement (Ofsted, 1999a; Cole et al 1998; Visser, 2000; HAS, 1995).

Specialist provision
Despite the progress made in developing provision in mainstream schools, the demand for specialist provision has remained high. Schools are particularly unwilling to provide for serious and frequent offenders. High levels of family disturbance and experience of multiple disadvantage are closely linked to the population of pupils who attend EBD special schools and PRUs (Cole et al, 2003). However, mainstream head teachers are also reluctant to provide for pupils with acute psychiatric disorders, believing that they their needs should be met by the highly specialised and expensive Tier 4 CAMHS services (Cole et al, 1998).

Special school placement is more commonly triggered by overt and disruptive behaviour rather than by manifestations of emotional difficulties and disturbances (Grimshaw and Berridge, 1994; Cole et al 1998). Recent research has shown that the largest group, by far, of pupils in maintained and non-maintained residential provision is those with BESD. They represent 35% of the total group of 2061 children. The great majority are of secondary age. The research also shows that, amongst the schools with residential accommodation, those providing for BESD are also the most numerous. They represent one fifth of all maintained and non-maintained special schools with boarders (Pinney, 2005).

In 2003, 77% of LEAs maintained one of more EBD school, 84% had one or more PRUs, 17% had PRUs but no EBD school of their own, while only 4% had neither PRU nor EBD school (Cole et al, 2003). LEAs lacking their own special schools or facilities accessed those in other LEAs or independent schools. Ofsted also reported an increasing number of EBD pupils in special schools and in the number of special schools providing for such pupils (Ofsted, 2003). But there has been a significant reduction (19%) in the numbers placed in residential schools (Cole et al, 1999, 2003) and a more flexible pattern of residential usage (Ofsted, 1999a). Special or residential school placement can result in children and young people losing contact with their family and local community and Ofsted (1999a) stresses the importance of maintaining close links wherever possible.

SOCIAL CARE

Looked after children and young people
The underachievement and social problems of looked after children have been highlighted in a number of studies (House of Commons Health Committee, 1998; DfEE, 1999). In March 2004 there were 61,000 children in public care in England, so this represents a major problem.

Various studies have found that up to a third of looked after children at any one time are out of school or excluded (Sinclair et al, 1998; Ofsted, 1995). A high proportion of looked after children are known to have challenging behaviour and to have experienced different kinds of abuse prior to coming into care. Many also have educational difficulties, including special needs, which can lead to exclusions. Looked after

children are estimated to be ten times more likely to be excluded from school compared with children in general (Warren, 1997).

Statutory guidance in 2000 emphasised that policy and practice in local authorities should be based on a broader 'corporate parenting' approach, and the Children's Act 2004 has introduced a duty on local authorities to promote the educational welfare of looked after children. However, whilst increased resources have been made available through initiatives such as Quality Protects, progress towards improvements have been slow (DOH, 2004). Change has been inhibited by problems of capacity in the social care workforce, a lack of resources and shortcomings in communication and joint working arrangements between different departments (Social Exclusion Unit, 2004).

Research continues to highlight barriers to educational progress resulting from the care system itself, especially where there are frequent changes in the child's placement (Social Exclusion Unit, 2003) and where foster parents receive insufficient information about the children's personal needs and educational backgrounds (Selwyn et al, 2004). However, there is growing evidence about factors that promote good practice. One study has highlighted the importance of having a key individual working at senior level who can cross-departmental boundaries and influence decision-making (Harker, 2004).

Support for young people
Young people can also be helped to develop skills and confidence in managing their situation through effective personal support programmes that build 'resilience' (Jackson et al, 1998; Dearden, 2004). Research also highlights the need for young people in the care system to develop networks of friends and involvement in activities outside their placements (Allin, 2001). The provision of support for families as well as community-based initiatives that help build and maintain social contacts can be effective in helping young people overcoming their problems (Newman, 2002).

Support for families
Home-school support workers and programmes such as those developed by the Home Office Programme Development Unit can bring about a reduction in permanent exclusions (Smith, 2002). Structured parenting group programmes, such as 'Positive Parenting' and 'Effective Parenting', have been successful in teaching child development and behaviour management of problem behaviour (Buchanan, A., 1998; MHF. 1999).

Liaison between service providers
Good liaison between service providers is considered to be crucial, with professionals have a clear understanding their respective roles and responsibilities. In many authorities behaviour support services work with looked after children and some have teachers who are jointly funded by education and social services (Morgan, 1999; DOH, 2000). Continuing training for all staff, including those who work in care homes, is considered essential (Social Exclusion Unit, 2003; Harker et al, 2004; Dearden, 2004).

HEALTH/MENTAL HEALTH

Incidence
A survey published in 2000 showed that 10% of children between 5-15 had a mental health problem (Stationery Office, 2000). The three most common groups of childhood mental health problems were:
- Emotional disorders (depression, anxiety, obsessions)
- Hyperactivity (inattention, over-activity)
- Conduct disorders (awkward, troublesome, aggressive and anti-social behaviour)

Mental health problems are strongly linked to social and environmental factors (Stationery Office, 2000). The causes of childhood depression include: bereavement, family break-up, bullying, moving home and/or school, having a parent with mental illness, tension in the family, acquiring a new step-family, fear of failure, being abused and worrying about the future (Young Minds, 1995).

Vulnerable groups

Looked after children and young people are especially susceptible to mental health problems. One recent study found that 11% had emotional disorders, 36% had conduct disorders, and 11% had hyperkinetic disorders (Meltzer et al, 2000). Another found that 67% of those in the care system, and 96% of those in children's homes or secure units had clinical levels of psychotic illness (Buchanan and Ten Brinke, 1998).

Young offenders are also prone to develop mental health problems and are thirteen times more likely than other children to be looked after and twenty times more likely to have been excluded from school. 90% of the young people aged 15-20 in jail have a diagnosed mental illness, a substance abuse problem, or both (McCann et al, 1996).

Availability of mental health services
The Children's Act 2004 places a duty on local authorities and other agencies caring for children to co-operate and take part in joint arrangements. The National Service Framework for Children, Young people and Maternity Services (NSF) set out national standards for children's health and social services (DOH, 2004). Children's Trusts have a primary role in securing integrated commissioning, leading to a more integrated service delivery.

There is a growing recognition of the risk factors associated with mental health problems and the importance of taking preventative action in order to avert later problems. However, it is generally conceded that there is insufficient time and resources to respond to the increasing demand on mental health services. The Audit Commission report 'Children in Mind' (1999) revealed large discrepancies in mental health spending and staffing. 29% of Trusts had only limited services for children.

Support for schools and other service providers
The amount of time available to support mainstream and special schools in their work with pupils with EBD has been very limited (HAS, 1995; Ofsted, 1999a). In 2000 the Social Exclusions Unit Policy Action Team 12 reported on critical gaps in individual services, with access being described as a 'postcode lottery (Cabinet Office, 2000). Two years later, an inquiry highlighted widespread problems of accessing services for young people with learning difficulties (MHF, 2002). Research commissioned by the DfES highlighted the need for CAMHS to develop joint working and to have stronger links with other services supporting children (Pettitt, 2003).

Parent support
The importance of early intervention for behaviour problems with young children has been highlighted in a number of studies (Polnay, 2000; Mathieson and Sanson, 2000). Where children exhibit aggressive, anti-social, challenging or disturbing behaviour, parents often need emotional support and practical help to manage the home situation. The tensions can increase as children get older and bigger and face the problems associated with adolescence (Mind booklets). Group-based parenting programmes have been found to be effective in changing parenting practice and improving behaviour in young children (Barlow, 1999). However despite the rapid expansion in the number of group-based parenting programmes there is no framework for systematic provision of for a quality assurance structure (Smith, 1996).

Talking treatments
Interventions such as counselling and psychotherapy are used to treat depression, anxiety, and aggressive behaviour. Talking treatments are widely used and are usually offered by clinical/educational psychologists and trained counsellors.

Awareness and Skills-based programmes
Programmes such as GOAL are offered through workshops either in schools or in youth centres to raise awareness about health enhancing and health compromising behaviours (Buchanan, 1999).

Cognitive behavioural therapy
This is a widely established approach based on the theory that our behaviour and beliefs are learned and therefore can be unlearned, or reframed. It has been found to be effective for a variety of mental health problems such as phobias, obsessions and eating disorders.

Medication
There is renewed debate about the ethics and effectiveness of using medication to treat children with behavioural difficulties, and ADHD in particular. Medical consensus is divided, but there seems to be general agreement that doctors should use pharmacology only sparingly in treating children and young people with behaviour disorders, and always in conjunction with talking treatments or other behaviour management training (BMJ, 2004). Nevertheless, many children with mental health problems are increasingly offered medication as the sole treatment for their condition (BMJ 2004). While many parents believe that their child's welfare and progress has been greatly helped by the use of such drugs as Ritalin, concern is rising about the increase in usage of Ritalin to manage children's behaviour (Timini, 2005). The rate of prescription for Ritalin and Concerta was fifty seven times higher in 2004 than it had been in 1994.

Child and Adolescent psychiatric services
These are services that treat children and young people on an in-patient or outpatient basis in hospitals and child and family centres. Treatment is offered by psychiatrists, clinical psychologists and other members of the clinic team.

Therapeutic communities
These provide residential accommodation for young people over the age of 13 experiencing severe emotional problems and highly disturbed behaviour. A range of therapeutic approaches is used. The high staff to young person ratio and the therapeutic element mean they are expensive to run (Jarvis, 1991).

REFERENCES

Allin, P (2001) *The Value of Sport and the Arts.* Quality Protects research briefings 4. London: Department of Health

Audit Commission (1999) *Children in Mind: Child and Adolescent Mental Health Services.* London: Audit Commission

Audit Commission (2000) *Another Country.* Audit Commission

Ayers, H., Clarke, D. and Murray, A. (2000) (2nd Edition*) Perspectives on Behaviour: A Practical Guide to Effective Interventions for Teachers.* London: David Fulton Publishers

Barlow, J. (1999) *Systematic Review of the Effectiveness of Parent-Training Programmes in improving Behaviour Problems in Children aged 3-10 years.* University of Oxford, Health Services Research Unit

Bell, D. (2005) *A 21st Century Curriculum for 14-19 Year olds.* Speech to the Texas Lyceum Association 25th Anniversary Conference

Bennathan, M., and Boxall, M. (1996) *Effective Intervention in Primary Schools: Nurture Groups.* London: David Fulton Publishers

Bennathan, M. (1998) *The Boxall profile: Handbook for Teachers.* Maidstone: AWCEBD

Bennathan, M. (2003) Proving that nurture groups work. *SEBDA News*

Berridge, D. and Sinclair, R. (1999*) Improving the Education of Children in Public Care Through a Whole Authority Approach: Proposal to evaluate the 'ideal authority' development project.* University of Luton and national Children's Bureau

Berrridge, D., Brodie, I., Cole, T., Daniels, H., Knapp, M., and McNeill, V. (2002) *Costs and Consequences of Services for Troubled Adolescents: an Exploratory, Analytic Study.* Luton: University of Luton

BMJ (2004) *Rapid Responses.* British Medical Journal: October edition

Buchanan, A., Ten Brinke, J-A. (1998) *Recovery from Emotional and Behavioural Problems.* NHS Executive, Anglia and Oxford: University of Oxford

Chazan, M., Laing, A., and Davies, D. (1994) *Emotional and Behavioural Difficulties in Middle Childhood. London:* Falmer

Children's Act 2004. London. TSO

Coates, S., and James, G. (1995) Opportunities for Students with Autism. *Skill Conference workshop.* www.autism.org.uk/autismdata

Cole, T., Visser, J., and Upton, G. (1998) *Effective Schooling for Pupils with Emotional and Behavioural Difficulties.* London: David Fulton Publishers

Cole, T., Daniels, H., and Visser, J. (1999) *Patterns of Educational Provision Maintained by LEAs for Pupils with Behavioural Problems*. Report sponsored by Nuffield Foundation. Birmingham: University of Birmingham

Cole, T., Daniels, H., Berridge, D., Brodie, I., Beecham, J., Knapp, M. and McNeill, V. (2003) *Residential Schools for Pupils with Emotional and Behavioural Difficulties: Client and Organisational Characteristics*. Birmingham: University of Birmingham

Croll, P. (2001) 'Children with statements in mainstream key stage two classrooms: a survey in 46 primary schools' *Educational Review*, 53,**2**

Daniels, H., Visser, J., Cole, T., de Reybekill, N, Harris, J., and Cumella, S. (1998b) *Educational Support for Children with Mental Health Issues; Including the Emotionally Vulnerable.* Report for the City of Birmingham/ Birmingham Health Authority. Birmingham: University of Birmingham

Dearden, J. (2004) 'Resilience: A study of risk and protective factors from the perspective of young people with experience of local authority care', *Support for Learning,* 19, **4**, 187-93

Department of Health, Social Services Inspectorate/Ofsted (1995) *The Education of Children who are Looked After by Local Authorities*. Ofsted

Department of Health (2000) *Promoting Health for Looked After Children: a Guide to Healthcare Planning, Assessment and Monitoring.* Consultation Document. London: Department of Health

Department of Health (2000) *Guidance on the Education of Children and Young People in Public Care.* DfES and DOH

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Standard 9, the mental and psychological well-being of children and young people.* London: Department of Health

Department of Health (2004) *Transforming Children's Services: An evaluation of local responses to the Quality Protects programme.* London: Department of Health

DfE (1994b) *The Education of Children with Emotional and Behavioural Difficultie*s, Circular 9/94. London: Department for Education

DfE(1994c) *Code of Practice for the Identification and Assessment of Special Educational Needs.* London: HMSO

DfEE (1998b) *LEA Behaviour Support Plans. Circular 1/98*. DfEE

DfES (2002) *Good Practice Guidelines for Learning Support Units*. London: Excellence in Cities DfES

DfES (2005) *National Statistics: First Release, Special Educational Needs in England*. DfES

Harris, N., Eden, K., and Blair, A. (2000) *Challenges to School Exclusion*. London: Routledge

Galloway, D., Armstrong, P., and Tomlinson, S. (1994) *The Assessment of Special Educational Needs*. London: Longman

Galvin, P. and Costa, P. (1994) Building Better Behaved Schools: Effective support at whole school level. In P. Gray, A. Miller and J. Noakes (Eds) *Challenging Behaviour in Schools.* London. Routledge

Goddard, J. (2000) 'Research review; the education of looked after children', *Child and Family Social Work,* 5, **1**, 79-86

Graham, P., Hughes, C. (1995) *So Young, So Sad, So Listen.* London; Gaskell

Grimshaw, R., and Berridge, D. (1994) *Educating Disruptive Children.* London: National Children's Bureau

Harker, R. et al (2004) *Taking Care of Education: An evaluation of the education of looked after children.* London: National Children's Bureau

Jarvis, M. (February 1991) Social Work Today

Kauffman, J. (2001*) Characteristics of Emotional and Behavioural Disorders of Children and Youth. New Jersey*: Merrill Prentice Hall

Kelly, D., and Gray, C. (2000) *Educational Psychology Services (England): Current Role, Good Practice and Future Directions.* London: DfEE

Kent, T (March 2000) The British Government to expand the use of drugs to control children's behaviour. *World Socialist website*

Lacey, P. (2001) 'The role of learning support assistants in the inclusive learning of pupils with severe and profound learning difficulties'. *Educational Review*, 53, **2**, pp 157-169

Lindsay, G. (1997) 'Are we ready for inclusion?'. In Lindsay, G. and Thompson, D. (Eds) *Values into Practice in Special Education.* London: David Fulton Publishers

Mathieson, K.S., Sanson, A. (2000) 'Dimensions of Early Childhood Behaviour Problems: Stability and predictors of change from 18-30 months'. *Journal of Abnormal Psychology*. Feb 2000

Meltzer, H., Corbin, T., Gatward, R., Goodman, R. and Ford, T. (2002) *The Mental Health of Young People Looked After by Local Authorities in England.* Summary report: ONS

Mental Health Foundation (1999) *Bright Futures: Promoting Children and Young People's Mental Health.* London: Mental Health Foundation

Miller, A. (1996) *Pupil Behaviour and Teacher Culture.* London. Cassell

Mind (2000) Children and Young People and Mental Health: Fact sheets and booklets. London: Mind

Morgan, S. (1999) *Care About Education: A joint training curriculum for supporting children in public care.* National Children's Bureau

Munn, P., Lloyd, G., and Cullen, M. (2000*) Alternatives to School Exclusion.* London: Paul Chapman

Newman, T. (2002) *Promoting Resilience: A Review of Effective Strategies for Care Services, Prepared for the Centre of Evidence-based Social Services.* Exeter: University of Exeter

Ofsted (1995) *Annual report of Her Majesty's Chief Inspector of Schools.* London: Ofsted

Ofsted (1999a) *Principles into Practice: Effective Education for Pupils with EBD.* HMI report. London: Ofsted

Ofsted (2001, 2002, 2003) *Annual report of her Majesty's Chief Inspector for Schools: Standards and Quality in Education.* London: Ofsted

Pettitt, B. (2003) *Effective Joint Working between Child and Adolescent Mental Health Service and Schools.* Research Report 412. London: DfES

Polnay, L. (2000) *Continuity of Behaviour Problems from Infancy to Early Adulthood.* The Research Findings Register. Summary number 296

Psychominded, October 2005: *ADHD is biobabble.* www.psychominded.co.uk

Quality and Curriculum Authority (2001) *Supporting School Development: Emotional and Behavioural Development.* London: QCA/DfEE

Selwyn, J. and Quinton, D. (2004) 'Stability, permanence, outcomes and support: foster care and adoption compared' *Adoption and Fostering*, 28, 4, 6-15

Sigafoos, J., Ottendreigh, N., and Pennell, N. (1997) *'Parent and teacher ratings of challenging in young people with developmental disabilities'*, British Journal of Learning Disabilities, 25, **1**, pp13-17

Smith, C. (1996) *Developing Parenting Programmes.* National Children's Bureau

Smith, R. (2002*) Promoting Children's Emotional Health.* Barnardos

Sinclair, I. and Gibbs, I (1998*) Children's Homes: A study in diversity.* Wiley

St James-Roberts, I and Singh, C.S. (2001) *Can Mentors Help Primary School Children with Behaviour Problems.* Home Office research Study 233. London: Home Office Research, Development and Statistics Directorate

Social Exclusion Unit (2003) A *Better Education for Children in Care.* London: Social Exclusion Unit

Stationery Office (2000) *Mental Health of Children and Adolescents in Great Britain.* London: Department of Health

Tarling, R., Burrows, J. and Clarke, A. (2000) *Dalston Youth Project Part 11 (11-14): An evaluation.* London: Home Office

Thomas, G., Walker. D., and Webb, J. (1998) *The Making of the Inclusive School.* London: Routledge

Timini, S. (2005) *Naughty Boys: Anti-Social Behaviour, ADHD and the Role of Culture.* London: Palgrave MacMillan

Tolmac, J., and Hodes, M. (2004) Ethnic Variations Among Adolescent Psychiatric In-Patients with psychotic disorders. Br. J. Psychiatry, Vol 184, 248-431

Williams, H. (ed) (2001) Framework *for Intervention.* Birmingham City Council

Visser, J., Cole, T., and Daniels, H, (2002) 'Inclusion for the difficult to include' *Support for Learning*, 17, 1, pp 23-27

Visser, J. (2003*) A study of children and young people who present challenging behaviour.* Birmingham: University of Birmingham

Young Minds (1995) *Supporting Young Refugees.* Newsletter 22

4. OTHER LOW INCIDENCE NEEDS

The DfES Low Incidence SEN Review focused mainly on severe autistic spectrum disorders, behaviour difficulties and sensory/multi-sensory impairment. But there is range of other low incidence special needs for which local authorities have to make special provision. These include children with complex disabilities, which may include physical disability with associated learning difficulties, medical conditions, sensory impairment and difficulties communicating verbally. Whilst it was not within the scope of this project to fully address the needs of these young people, issues of provision for them were raised during the regional focus groups. Therefore some brief reference is made here in this literature review.

EDUCATION

Providing the right environment
The Ofsted report "Towards Inclusive Schools" examines the extent to which the Government's revised inclusion framework has impacted on the capacity of mainstream schools to cater effectively for pupils with a wider range of special educational needs. Factors which influence parental decisions to opt for special school or mainstream may include the perceived ability of each sector to provide an environment which is safe (particularly from bullying), is accessible and suitable (adapted toilets and changing areas of sufficient size), has staff with specialist knowledge (e.g. how to modify the curriculum), is able to provide for care and support as well as teaching and gives the pupil regular access to therapy (Ofsted, 2004).

Inclusive practices are key to ensuring full participation of all pupils (Lindsay 2003). But it is essential to listen to the messages of disabled pupils who experience the day-to-day realities of school life if we are to continue to develop meaningful inclusion (Wilson, 2004). A review commissioned by The Disability Rights Commission in 2002, and a more detailed follow-up including interviews with disabled students, found that provision in school was not always adequate. 45% of young people interviewed said they had experienced problems at school related to their disability, and 90% of these felt that these had impacted negatively on the educational achievements. 38% of pupils reported bullying, 41% had felt isolated due to their impairment. On the other hand 70% said they had been treated fairly, although one fifth felt their achievements were not valued in the same way as those of their non-disabled peers (Disability Rights Commission, 2002b). There are many models of good practice, with effective collaboration across special and mainstream schools (Miller et al 2005).

Specialist interventions and therapies
Many children and young people with physical disabilities require specialist interventions and therapies in order to maintain mobility and function so as to enable access to and participation in the curriculum. School-based therapies include physiotherapy, occupational therapy and speech therapy. Various fact-sheets produced by the national charity SCOPE explain therapies in common use (SCOPE, 2003). These include Bobath therapy, Botulinum Toxin, Conductive Education, Baclofen therapy, Lycra dynamic splinting, and Targeted Training.

Conductive education seeks to integrate a therapeutic approach to posture and movement with delivery of the curriculum. Although derived from a different educational philosophy in Hungary where the ability to walk was a pre-requisite of receiving schooling, the method has retained some credence in the UK, despite research findings which failed to find any clear advantage (Barstow et al 1993, Bax 1993). One of the main advantages in a UK setting where "conductors" are not always available, is the necessity for therapists and education staff to work closely together to deliver an integrated programme (Barstow et al, 1993).

Equipment and learning resources
Pupils with severe physical disabilities and related medical needs require a range of equipment needs such as standing frames, supportive seating, height-adjustable work-surfaces, walking frames and wheelchairs. Personal needs may include adapted toilets, changing beds, washing facilities and access to personal carers to attend to personal needs throughout the school day, and nursing care.

For youngsters with little or no speech alternatives include electronic "voice-output systems, requiring intensive input from therapy and school support services. Makaton or other signing and symbol systems

may also be required. Computers may be essential to enable children to record their work, and these may require adapted access devices such as touch-screens, switches, or specialised keyboards.

Transition

Transition from one phase of education to another, particularly at 16 plus can be especially difficult for disabled students. There is a need for a wider range of suitable courses and experiences. Vocational routes have often been tokenistic with more emphasis on care than on opportunity. There is also a need for a better system for funding of specialist equipment and support for students with additional needs, to promote a smooth transition between school and post-school pathways (Miller et al, 2005).

SOCIAL CARE

Accessing support

Access to social services is provided under The Children Act 1989 following assessment (Russell, 1994). In order to participate in normal leisure and social activities such as outings children may be offered a "link-worker" to act as a guide friend or advocate. Direct payments should now make it possible for families to employ someone of their choice to undertake this function. However Bamford and colleagues (Bamford et al, 1997) analysed customer satisfaction with care for children with cerebral palsy across medical educational and social care. Their findings, quoted by Middleton identified serious deficiencies in provision of care for social, psychological and emotional needs. Parents feel obliged to present their child's need in the most negative light in order to access strictly rationed services. The voluntary sector has a role in filling the gaps in provision but seeking help from charities can carry a stigma and "eligibility has to be proven. Provision is not a foregone conclusion and getting it usually takes time" (Barnes, 1994).

Respite care

Many families appreciate their entitlement to "respite care" which enables them to recharge their batteries and give more time and attention to their other children. However, this may not be appropriate for all children with severe physical and medical needs, especially where the child or young person has challenging behaviour. There are also potential risks for children being cared for away from home where they could be subject to abuse (Middleton, 1999). Disabled children in residential accommodation or foster care are less likely to receive independent visitors.

Community resources

The Audit Commission (2003) identified a national shortage of both inclusive and specialist provision across public, voluntary and private sectors. Very often there are gaps in play and leisure provision within a locality, for children in a particular age group and with certain needs. This can put pressure on the whole family. Parents are often unable to take the ordinary breaks from caring that other families enjoy (Audit Commission, 2003). Siblings also experience restriction in their own social lives. This may be arise from a lack of strategic co-ordination of services across the sector, or poor staff training at a provider level (Naylor and Prescott, 2004).

Housing

Housing and funding for adaptations poses a major problem for severely disabled children and their families. Families with a disabled child experience far greater problems with housing than families with non-disabled children, the most frequently reported problem being lack of space, for play, storage of equipment, carrying out therapies and other problems related to condition and access. Only a minority of families reported they had received assistance from statutory agencies to address their housing needs. Three-quarters of the families had not had their housing needs assessed by an occupational therapist. Among those identified as needing to make a contribution, one in three had been unable to meet the costs and the work had not been carried out (Joseph Rowntree Foundation, 2003).

HEALTH

Medical support

Disabled children and their parents are usually seen at Child Development Centres, which offer opportunities for interdisciplinary clinics and for parents to meet and provide mutual support (Middleton, 1999).

Organisations such as The British Institute for Brain-Injured Children continue to offer hope to parents, despite research evidence which failed to find any therapeutic advantage. The Royal College of Paediatrics and Child Health reached the conclusion that the intensive therapy programmes were 'uncertain, and that the discomfort to the children and the demands on the family may be considerable' (RCPCH 1997.

Family support
Bamford and colleagues analysed customer satisfaction with care for children with cerebral palsy across medical educational and social care. Their findings, quoted by Middleton, indicated high levels of satisfaction with core medical help and some key paramedics (Bamford et al, 1997). Best Practice Guidance, issued as part of the National Service Framework identifies a range of markers of good practice, including access for disabled children to all mainstream children's services. It made the following recommendations:
- services should promote active participation and inclusion
- young people and their families should receive child-centred multi-agency co-ordinated services from the point of referral through identification, assessment and delivery
- early intervention and interventions should support optimal physical, cognitive and social development, with minimal waiting times
- disabled children should have access to high-quality evidence-based care delivered by staff who have the right skills for diagnosis, assessment treatment, ongoing support and care.

Finally it stated that disabled young people and their families should be routinely involved and supported in making informed decisions about their treatment, care and support and in shaping services (DOH, 2004).

REFERENCES

Audit Commission Report (2003) *Services for Disabled Children.* London: Audit Commission
Bamford, D, Griffiths, H, Long, S, and Kernochan G (1997) Analysis of consumer satisfaction in cerebral palsy care. *Journal of Inter-professional Care 11, 187-93*
Barnes C. (1994) *Disabled People in Britain and Discrimination.* London: Hurst and Co.
Barstow, P, Cochrane, R and Hur, J (1993) *Evaluation of Conductive Education for Children with Cerebral Palsy.* DFE/University of Birmingham
Bax, M.C.O (1993) *Conductive education Assessed.* Dev. Med and Child Neurology, **35**, 659-60
Department of Health (2004) *National Service Framework for the Disabled Child.* London: DOH
Disability Rights Commission (2002b) survey conducted by NOP on behalf of DRC. London
Joseph Rowntree Foundation (2003) *The Housing Needs of Disabled Children: the national evidence.* Bristol: Joseph Rowntree Foundation
Lindsay, G (2003) Inclusive Education: a critical perspective. *British journal of Special Education* Vol 30 no. 1
Middleton, L (1996) *Making a Difference: Social Work with Disabled Children.* Birmingham: Venture Press
Middleton, L. (1999) *Disabled Children: Challenging Social Exclusion.* Birmingham: Venture Press
Miller, A., Keil, S., Cobb, R. (2005) *A Review of the Literature on Accessible Curricula, Qualifications and Assessment.* London: Institute of Education
Naylor, A, Prescott, P. (2004) Invisible Children? The need for support groups for siblings of disabled children. *British Journal of Special Education Vol. 31 no.4*
Ofsted (2004) *Special educational Needs and Disability: towards inclusive schools.* London: Ofsted
Royal College of Paediatrics and Child Health (1997) *A multi-disciplinary appraisal of the British Institute for Brain Injured Children 1995-97.* London, British Association for Community Child Health
Russell, P (1994) *The Children Act 1989: Children and young people with learning disabilities: Some opportunities and Challenges.* Manchester, National Development Team.
SCOPE (2003) *Introduction to Therapy.* Booklets

Wilson Louca-Mai (2004) Towards equality: the voices of young disabled people in Disability Rights Commission Research. *Support for Learning* Vol 19 no. 4

APPENDIX 4:   **QUESTIONNAIRE:**

<div style="border:1px solid black; background:#c0c0c0; padding:1em;">

INFORMATION ON THE QUESTIONNAIRE

</div>

This questionnaire is structured as follows:

3 sections: *(I) Severe[63]/profound sensory/multisensory impairment*
            (II) Severe autistic spectrum disorder
            (III) Severe behavioural, emotional and social difficulties

+ a final section (IV) on other areas of low incidence needs you consider to be particularly important

For each of these types of need, we are asking for your views/perceptions with regard to:

  1) The <u>importance</u> of a range of different 'elements of provision'
  2) Their <u>availability</u> in your local area
  3) Key elements of provision that you think need <u>further development</u>
  4) In which <u>provision/service area</u> developments should best be focused
  5) Levels of <u>confidence</u> in your local capacity to meet this type of needs

Please comment on all aspects of provision. We are asking for your own views/perceptions/experience. We are not expecting you to be an expert in each of these areas.

You may wish to consult others in making your response or complete the questionnaire jointly with colleagues. While this may well be valuable, please be conscious of the need to return your overall response by the deadline indicated.

---

[63] The definition of low incidence adopted here is not simply based on rarity of particular impairments but is more functional (with an emphasis on the need for complex multi-agency planning and specific arrangements to provide for the young person). You will need to form your own practical judgement about which young people fall within this definition, because this will be influenced to an extent by the local pattern of provision already in place.

SECTION I: SEVERE/PROFOUND SENSORY IMPAIRMENT

Includes deafness, visual impairment, multi-disabled visual impairment and multisensory impairment

1(a): Firstly, please tick in the boxes provided if you agree that each of the elements below is <u>important</u> in meeting the needs of children/young people with severe/profound sensory impairment.

(b): Secondly, please indicate how <u>available</u> each element is in your local authority area (by circling the appropriate number).

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
PROCESSES						
A1. Early identification and intervention	☐	1	2	3	4	5
A2. Multi-disciplinary assessment	☐	1	2	3	4	5
A3. Coordinated planning and review	☐	1	2	3	4	5
A4. Active involvement of parents and young people	☐	1	2	3	4	5
A5. Effective management of transitions (school phases; preschool to school; school to adulthood; following medical interventions)	☐	1	2	3	4	5
TYPES OF INPUT						
B1. Specialist pre-school provision in the home	☐	1	2	3	4	5
B2. Parent and Family education programmes	☐	1	2	3	4	5
B3. Teaching of skills needed by particular groups or individuals (eg BSL, Braille, keyboard skills, mobility)	☐	1	2	3	4	5
B4. Specific intervention approaches (eg tactile communication)	☐	1	2	3	4	5
B5. Specialist careers' advice	☐	1	2	3	4	5
B6. Particular medical interventions (eg cochlear implant)	☐	1	2	3	4	5
EXPERIENCES						
C1. Opportunities for collaborative learning and socialisation with peer group who have similar impairments	☐	1	2	3	4	5

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
C2. Opportunities for collaborative learning and socialisation with non-disabled peers	☐	1	2	3	4	5
C3. Access to appropriate range of 14-19 opportunities	☐	1	2	3	4	5
PROFESSIONAL SKILLS AND QUALITIES						
D1. Positive and inclusive staff attitudes	☐	1	2	3	4	5
D2. Skilled practitioners with experience of this kind of need and training/necessary qualifications	☐	1	2	3	4	5
SUPPORT TO CARERS AND PROFESSIONALS						
E1. Emotional/professional support for front-line workers	☐	1	2	3	4	5
E2. Support to parents and families	☐	1	2	3	4	5
E3. A suitable range of short break/ respite opportunities	☐	1	2	3	4	5
RESOURCES						
F1. Technology (eg to enhance residual hearing/vision)	☐	1	2	3	4	5
F2. Specialist equipment	☐	1	2	3	4	5
F3. Adaptations to the environment (eg low ambient noise; physical adaptations)	☐	1	2	3	4	5
F4. Suitable transport arrangements	☐	1	2	3	4	5

2: *Please list any <u>other</u> elements of provision that you consider to be important for this group, include them in the boxes below and give a rating of their availability in your local authority area.*

	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
G1.	1	2	3	4	5
G2.	1	2	3	4	5
G3.	1	2	3	4	5

3: *Please select three items from the lists above that are <u>insufficient</u> at present and which, if developed further, would make the <u>most significant difference</u> in helping meets the needs of this group locally. Please enter code numbers (eg. A3, G1, F5) below.*

1. _____

2. _____

3. _____

4: In what provision/service areas is <u>further development</u> needed in your local authority area to meet the needs of young people with severe to profound sensory impairment and their families? *Please circle.*

	Much Needed	Some Needed	Average Amount Needed	Little Needed	None Needed
H1. Early Years settings	1	2	3	4	5
H2. Primary mainstream schools	1	2	3	4	5
H3. Secondary mainstream schools	1	2	3	4	5
H4. Mainstream FE colleges	1	2	3	4	5
H5. Education support services	1	2	3	4	5
H6. Mainstream school resource bases (for this kind of need)	1	2	3	4	5
H7. Special school (for this kind of need)	1	2	3	4	5
H8. Other kinds of special school	1	2	3	4	5
H9. Specialist post 16 provision	1	2	3	4	5
H10. Foster parents	1	2	3	4	5
H11. Other forms of care provision (eg residential homes/units	1	2	3	4	5
H12. Field social work provision	1	2	3	4	5
H13. Universal health services (eg Health Visitors, nurses)	1	2	3	4	5
H14: Therapy services (eg. Speech, OT, Physio)	1	2	3	4	5
H15. Other specialist services (eg audiology)	1	2	3	4	5
H16. CAMHS/psychological service input	1	2	3	4	5
H17. Other medical services (eg. ENT)	1	2	3	4	5
H18. Youth/community services	1	2	3	4	5
H19. Connexions/careers services	1	2	3	4	5
H20. Voluntary/community support (befrienders/mentors etc)	1	2	3	4	5
H21. Transport services	1	2	3	4	5

5:   In which of the above areas do you feel developments would make the <u>most significant</u> impact on meeting the needs of children/young people with severe/profound sensory impairment in your local authority area ?
Please select three code numbers (eg. H3, H4, H6) from the list in 4 (above).

1. _____

2. _____

3. _____

6:   What <u>other</u> arrangements do you think are particularly important for this group and require significant further development in your local authority area ? *Please list below.*

_____

_____

_____

_____

_____

_____

7(a):   How confident are you in the current capacity of services/provision in your local authority area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Not very Confident   Not at all Confident

7(b):   How confident do you think parents and carers are about the current capacity of services/provision in your local authority area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Not very Confident   Not at all Confident

147

SECTION II: SEVERE AUTISTIC SPECTRUM DISORDERS (ASD)

1(a): *Firstly, please tick in the boxes provided if you agree that each of the elements below is <u>important</u> in meeting the needs of children/young people with severe autistic spectrum disorders.*

(b): *Secondly, please indicate how <u>available</u> each element is in your local authority area (by circling the appropriate number).*

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
PROCESSES						
A1. Early identification and intervention	☐	1	2	3	4	5
A2. Multi-disciplinary assessment	☐	1	2	3	4	5
A3. Coordinated planning and review	☐	1	2	3	4	5
A4. Active involvement of parents and young people	☐	1	2	3	4	5
A5. Effective management of transitions (school phases; preschool to school; school to adulthood; following medical interventions)	☐	1	2	3	4	5
TYPES OF INPUT						
B1. Specialist pre-school provision in the home	☐	1	2	3	4	5
B2. Parent and Family education programmes	☐	1	2	3	4	5
B3. Support for mental health issues	☐	1	2	3	4	5
B4: Behaviour management support	☐	1	2	3	4	5
B5. Family key worker	☐	1	2	3	4	5
B6. ASD specific teaching approaches (eg. TEACCH, PECS)	☐	1	2	3	4	5
B7. An eclectic range of other interventions/strategies/approaches (eg. visual/multi-sensory, social stories, music interaction)	☐	1	2	3	4	5
B8. Prescription and monitoring of medication	☐	1	2	3	4	5

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
EXPERIENCES						
C1. Opportunities for collaborative learning and socialisation with ASD peer group	☐	1	2	3	4	5
C2. Opportunities for collaborative learning and socialisation with non-disabled peer group	☐	1	2	3	4	5
C3. Access to supported social / leisure activities	☐	1	2	3	4	5
C4. Access to appropriate range of 14-19 opportunities	☐	1	2	3	4	5
PROFESSIONAL SKILLS AND QUALITIES						
D1. Positive and inclusive staff attitudes	☐	1	2	3	4	5
D2. Skilled practitioners with training and experience in ASD	☐	1	2	3	4	5
SUPPORT TO PROFESSIONALS AND CARERS						
E1. Emotional/professional support for front-line workers	☐	1	2	3	4	5
E2. Support to parents and families	☐	1	2	3	4	5
E3. A suitable range of respite opportunities	☐	1	2	3	4	5
E4. Multi-agency ASD training for professionals	☐	1	2	3	4	5
E5. Access to training in positive handling techniques	☐	1	2	3	4	5
E6. Access to information about ASD services / organisations	☐	1	2	3	4	5
RESOURCES						
F1. Specialist technology and software (eg. to support communication)	☐	1	2	3	4	5
F2. Adaptations to the school environment	☐	1	2	3	4	5
F3. Adaptations to the home/ community environment	☐	1	2	3	4	5
F4. Suitable transport arrangements	☐	1	2	3	4	5

2: *Please list any <u>other</u> elements of provision that you consider to be important for this group, include them in the boxes below and give a rating of their availability in your Authority/PCT.*

	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
G1.	1	2	3	4	5
G2.	1	2	3	4	5
G3.	1	2	3	4	5

3: *Please select three items from the lists above that are <u>insufficient</u> at present and which, if developed further, would make the <u>most significant difference</u> in helping meets the needs of this group locally. Please enter code numbers (eg. A3, G1, F5) below.*

1. _____

2. _____

3. _____

4: **In what provision/service areas is <u>further development</u> needed in your local authority area to meet the needs of young people with severe autistic spectrum disorders and their families?** *Please circle.*

	Much Needed	Some Needed	Average Amount Needed	Little Needed	None Needed
H1. Early Years settings	1	2	3	4	5
H2. Primary mainstream schools	1	2	3	4	5
H3. Secondary mainstream schools	1	2	3	4	5
H4. Mainstream FE colleges	1	2	3	4	5
H5. Education support services	1	2	3	4	5
H6. Mainstream school resource bases (for this kind of need)	1	2	3	4	5
H7. Special school (for this kind of need)	1	2	3	4	5
H8. Other kinds of special school	1	2	3	4	5
H9. Specialist post 16 provision	1	2	3	4	5
H10: Foster parents	1	2	3	4	5

	Much Needed	Some Needed	Average Amount Needed	Little Needed	None Needed
H11. Other forms of care provision (eg residential homes/units)	1	2	3	4	5
H12. Field social work provision	1	2	3	4	5
H13. Universal Health services (eg Health Visitors, nurses)	1	2	3	4	5
H14. Therapy services (eg. Speech, OT, Physio)	1	2	3	4	5
H15. CAMHS services	1	2	3	4	5
H16. Clinical psychology input	1	2	3	4	5
H17. Youth/community services	1	2	3	4	5
H18. Connexions/careers services	1	2	3	4	5
H19. Voluntary/community support (befrienders/mentors etc)	1	2	3	4	5
H20. Transport services	1	2	3	4	5

5:   In which of the above areas do you feel developments would make the <u>most significant</u> impact on meeting the needs of children/young people with severe ASD in your local authority area ? *Please select three code numbers (eg. H3, H4, H6) from the list above.*

1. _____

2. _____

3. _____

6:   What <u>other</u> arrangements do you think are particularly important for this group and require significant further development in your local authority area ? *Please list below.*

_____

_____

_____

_____

_____

_____

7(a):   How confident are you in the current capacity of services/provision in your local authority area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Not very Confident   Not at all Confident

7(b):   How confident do you think parents and carers are about the current capacity of services/provision in your local authority area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Not very Confident   Not at all Confident

SECTION III: SEVERE BEHAVIOURAL, EMOTIONAL AND SOCIAL DIFFICULTIES (BESD)

1 *(a): Firstly, please tick in the box provided if you agree that each of the elements below is <u>important</u> in meeting the needs of children and young people with severe behavioural, emotional and social difficulties.*

(b): Secondly, please indicate how <u>available</u> each element is in your local authority area (using the rating scales).

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
PROCESSES						
A1. Appropriate school ethos, inclusion policies, and support systems	☐	1	2	3	4	5
A2. Timely identification of needs, and provision of support	☐	1	2	3	4	5
A3. Active involvement of parents and young people	☐	1	2	3	4	5
A4. Co-ordinated planning, review, pupil tracking, and placement procedures	☐	1	2	3	4	5
A5. Effective management of transitions (school phases; preschool to school; school to adulthood)	☐	1	2	3	4	5
TYPES OF INPUT						
B1. Stimulating, appropriate and accessible curriculum	☐	1	2	3	4	5
B2. Effective teaching for a range of learning styles	☐	1	2	3	4	5
B3. Clear and achievable steps for educational and social development. Positive feedback for achievement.	☐	1	2	3	4	5
B4. Supported social / leisure opportunities (eg sports, arts, outward bound)	☐	1	2	3	4	5
B5. Direct teaching of specific skills (eg.social skills, anger management)	☐	1	2	3	4	5
B6. Skilled support for mental health issues	☐	1	2	3	4	5
B7. Medical / specialist input (eg. regulation of diet, medication)	☐	1	2	3	4	5

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
EXPERIENCES						
C1. Satisfaction in achieving academic and social goals	☐	1	2	3	4	5
C2. Experiences of being valued (both individually and within groups)	☐	1	2	3	4	5
C3. Access to an appropriate range of 14-19 opportunities (including vocational / prevocational packages, positive work placements)	☐	1	2	3	4	5
C4. A supportive and safe family / care environment	☐	1	2	3	4	5
PROFESSIONAL SKILLS AND QUALITIES						
D1. Positive and inclusive staff attitudes	☐	1	2	3	4	5
D2. Ability to teach pupils with a wide range of aptitudes	☐	1	2	3	4	5
D3. Skilled practitioners with training and experience in BESD	☐	1	2	3	4	5
SUPPORT TO PROFESSIONALS & CARERS						
E1. Emotional/professional support for front-line workers	☐	1	2	3	4	5
E2. Support to parents/carers and families	☐	1	2	3	4	5
E3. Training for parents/carers in training skills	☐	1	2	3	4	5
E4. Support for school staffs in developing positive and inclusive approaches to pupil management and support	☐	1	2	3	4	5
E5. Training for various professionals in approaches to behaviour management / support approaches (eg. anger management, counselling)	☐	1	2	3	4	5
E6. Suitable range of short break/ respite opportunities	☐	1	2	3	4	5
E7. A range of skilled and resilient foster placements	☐	1	2	3	4	5

	Important (please tick)	Completely Available	Mostly Available	Available to some extent	Mostly Unavailable	Completely Unavailable
RESOURCES						
F1. Good quality accommodation (eg. on/offsite school) for pupils excluded from lessons/school, or requiring individual or small group support	☐	1	2	3	4	5
F2. Good quality care environment (eg where child is looked after)	☐	1	2	3	4	5
F3. Suitable arrangements for transport (eg. to offsite provision,	☐	1	2	3	4	5

2: *Please list any <u>other</u> elements of provision that you consider to be important for this group, include them in the boxes below and give a rating of their availability in your local authority area.*

	Completely Available	Mostly Available	Available to some extent	Mostly unavailable	Completely Unavailable
G1.	1	2	3	4	5
G2.	1	2	3	4	5
G3.	1	2	3	4	5

3: *Please select three items from the lists above that are <u>insufficient</u> at present and which, if developed further, would make the <u>most significant difference</u> in helping meets the needs of this group locally. Please enter code numbers (eg. A3, G1, F5) below.*

1. _____

2. _____

3. _____

4: **In what provision/service areas is <u>further development</u> needed in your local authority area to meet the needs of young people with severe BESD and their families?** *Please circle.*

	Much Needed	Some Needed	Average Amount Needed	Little Needed	None Needed
H1. Early Years settings	1	2	3	4	5
H2. Primary mainstream schools	1	2	3	4	5
H3. Secondary mainstream schools	1	2	3	4	5
H4. Mainstream FE colleges	1	2	3	4	5
H5. Education support services	1	2	3	4	5

H6. Mainstream school resource bases (for this kind of need)	1	2	3	4	5
H7. Special school (for this kind of need)	1	2	3	4	5
H8. Other kinds of special school	1	2	3	4	5
H9. Specialist post 16 provision	1	2	3	4	5
H10: Foster parents	1	2	3	4	5
H11. Other forms of care provision (eg residential homes/units)	1	2	3	4	5
H12. Field social work provision	1	2	3	4	5
H13. Universal Health services (eg Health Visitors, nurses)					
H14. Therapy services (eg. SALT, OT, Physio)	1	2	3	4	5
H15. CAMHS/psychological service input	1	2	3	4	5
H16. Youth/community services	1	2	3	4	5
H17. Connexions/careers services	1	2	3	4	5
H18. Youth Justice/Youth Offending services	1	2	3	4	5
H19. Voluntary/community support (befrienders/mentors etc)	1	2	3	4	5
H20. Transport services	1	2	3	4	5

5:   In which of the above areas do you feel developments would make the <u>most significant impact</u> on meeting the needs of children and young people with severe BESD in your local authority area ?
Please select three code numbers (eg. H3, H4, H6) from the above list.

1. _____

2. _____

3. _____

6: What <u>other</u> arrangements do you think are particularly important and require significant further development in your local authority area ? *Please list below*.

_____

_____

_____

_____

_____

_____

_____

7(a): How confident are you in the current capacity of services/provision in your local area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Slightly Confident   Not at all Confident

---

7(b): How confident do you think parents and carers are about the current capacity of services/provision in your local area for meeting the needs of this group? *Please circle.*

Very Confident   Quite Confident   Moderately Confident   Slightly Confident   Not at all Confident

SECTION IV: FINAL

1:   Are there any other types of Low Incidence needs (other than the 3 main categories included in this questionnaire) where provision in your area needs particular development? *Please list below.*

_____

_____

_____

2:   What kinds of developments for these groups would, in your view, lead to the greatest improvements? *Please list below. Refer, if necessary, to the list of options given in previous sections of the questionnaire.*

_____

_____

_____

_____

_____

_____

London Authorities, please fill in section V in addition to this.

Many thanks for your time.

SECTION V: LONDON AUTHORITIES ONLY

1:   Are there any other kinds of needs where you currently have to make provision out of your Authority (in the independent maintained sector, or in other LEA-maintained special schools and mainstream units / resource bases)? *Please give examples.*

_____

_____

_____

_____

_____

2:   What are the main reasons, in your view, why such placements currently need to be made? *Please circle.*

	Very Often	Often	Sometimes	Infrequently	Rarely
J1. Lack of suitable specialist provision/skills within Borough	1	2	3	4	5
J2. Insufficient places in own LEA specialist schools	1	2	3	4	5
J3. Parental choice	1	2	3	4	5
J4. Lack of suitable respite care options	1	2	3	4	5
J5. Need for specialist health provision	1	2	3	4	5

APPENDIX 5(a): BREAKDOWN OF REGIONAL FOCUS GROUP ATTENDERS

Region	Number of Authorities	Number represented	Number (Education)	Number (Health)	Number (SSD)	Regional	Vol.orgs (sens)	Vol.orgs (ASD)	Vol.orgs (BESD)	Vol.orgs (other)	NASS	PPO	LEA M/s	LEA special	Other
NE	12	12	12	7	2	1 SENRP 1 VP	2	1	0	2	1	1	0	2	8
Yorks	15	13	17	6	5	1 SENRP 2 CAMHS 1 VP 1 RChAdv	2	1	0	2	1	0	1	2	4
NW/GM	22	19	26	6	7	2 SENRPS 2 CAMHS	0	1	0	2	4	0	2	2	15
Eastern	10	10	12	5	6	1 SENRP 1 CAMHS	1	1	1	1	1	0	0	0	5 (3 FE)
EMids	9	8	9	2	4	2 SENRPs	2	1	0	0	1	0	0	3	2
WMids	14	13	13	5	5	2 SENRPs 1 VP	1	1	0	0	1	1	1	0	2
SC/SE	20	18	14	8	4	1 SENRP 1 CAMHS	4	1	1	2	1	1	0	1	5
SW	15	12	10	5	7	2 SENRP 2 CAMHS	1	1	0	2	1	0	0	1	0
LonNC	6	5	8	2	3	1 SENRP 1 VP	0	0	0	0	0	0	1	0	2
LonNE	8	8	11	1	2	(1 SENRP) 1 CAMHS	0	0	0	1	0	1	0	1	0
LonSE	6	6	7[64]	2	3	(1 SENRP)	2	1	0	0	0	1		2	2
LonSW	6	5	9[65]	2	3	(1 SENRP)	1	0	0	0	0	1	1	1	1
LonW	7	7	9	3	2	(1 SENRP) 1 VP	1	1	0	0	0	1	0	1	1
TOTAL	150	136 (91%)	157	54	53	12 SENRPs 9 CAMHS 5 VP 1RCA	17	10	2	12	11	7	6	16	47

Overall total attendance = 392

('Other' includes DfES guests, LSC/FE/Connexions, Government Officers (regions), and other relevant agencies)

---

[64] One from London SW
[65] One from London NE

APPENDIX 5:   FOCUS GROUPS:

(b) example programme:

*DfES audit of provision and services for children with low incidence needs/
ALCEO/London Challenge out-borough placements project*

London South East subregional focus group

14th October 2005: DfES Caxton House

9.00 – 9.30am	**Arrival/registration and coffee**
9.30 – 11.00am	**Session 1: Severe sensory/multi-sensory impairment**
11.00 – 11.30am	**Coffee**
11.30 – 1.00pm	**Session 2: Severe BESD**
1.00 – 2.00pm	**Lunch**
2.00 – 3.30pm	**Session 3: Severe autism + challenging behaviour**
3.30 – 4.00pm	**Final session: Other LI needs and out-Borough issues**

For each LI needs group session, there will be a 15 minute presentation on key findings from the national questionnaire and the regional picture. This will be followed by smaller group discussion and a plenary.

Aims of the day:

a) to share some of the key findings (national/regional) emerging from the questionnaire

b) to gather views from a broader range of local/regional stakeholders on significant gaps in provision for children with LI needs

c) to work towards a creative consensus on possible ways forward locally and regionally (including options for the role/contribution of regional centres of expertise).

(c) group discussion items:

1. Consider the elements of provision that would make the biggest difference at local/regional level in meeting the needs of children with this kind of difficulty.

- What is significant about these priorities from your point of view?
- Any shortfalls in this area which affect your capacity to provide locally?
- Any other aspects of provision that you think are equally significant?

2. How are we currently trying to address these priorities locally/regionally ?

(examples of good practice in the region which might be extended/used as a regional model?)

3. What needs to happen now or in the future to address the main priorities for development and how could this best be done?

>   a) local authority level?
>   b) regional/sub-regional level?

4. How would a 'Regional Centre of Expertise' address this area of need ?

>   a) what would it consist of?
>   b) how would it operate?