



Section 4 Home Based Programmes

**A Report on Current Practice by Local Education Authorities in the
West Midlands regarding the Provision of Home Based Programmes
For Children/Young People with an Autistic Spectrum Disorder**

**West Midlands
SEN Regional Partnership**

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Section 4 Home-based Programmes

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Home-based Programmes

1. Foreword

Concern was expressed by the West Midlands Local Education Authorities (LEAs) in November 1998, that some members were supporting families now choosing to educate their children with autistic spectrum disorders (ASDs), using intensive, home-based programmes based on the principles of the Lovaas or Option approaches. A range of practice with regard to requests for funding was evident across the region and it was felt that such diversity of practice continued to support fragmented and non-cohesive provision, against the ethos of the Government's Green Paper – Excellence for all Children (Oct.97).

At the same time, the parents' organisation 'Parents for the Early Intervention of Autism in Children' (PEACH) provided evidence that many LEAs in the north and south of the country had in fact been supporting programmes financially for some considerable time. PEACH boasts a membership of 800 people nationally. This includes the families of approximately 650 children with an ASD of which approximately 300 families are implementing an ABA/Lovaas style programme. It was evident that requests for home-based programmes within the West Midlands was a relatively new phenomenon compared with many other parts of the country where they had become firmly established within a range of provision e.g. Cheshire and Manchester.

The West Midlands Regional Co-ordination Project – SEN, (now known as the West Midlands SEN Regional Partnership) was therefore, set the task of “analysing existing programmes used to support children with autism: Lovaas, Son-Rise Option, etc.”

It has become clear that many authorities have invested significant sums of money in ABA/Lovaas type programmes. For example, a consortium of LEAs in the south of the country have commissioned Southampton University to carry out a research study on the children involved. When the study began in 1999, the total joint cost of the consortium's programmes was in excess of £500,000.

There is also evidence however, across the country, which suggests families are receiving very different responses to requests for funding from different LEAs. For example, two children living in the same street, but separate London boroughs, received different responses to their requests: Islington agreed funding whilst Hackney refused. Consequently children's educational choices have been decided by their postcode. Families have found this unacceptable and lobbying through pressure groups such as Parents Autism Campaign for Education (PACE) has raised political awareness of these inequalities.

The situation is further complicated by a minority of advocates who claim that ABA/Lovaas programmes not only provide a 'cure' for autism, but that they are the only validated treatment for autism. Whilst these statements are questionable, it is clearly a powerful argument to present to parents who have the responsibility of ensuring that their child receives the best intervention available.

LEAs are nervous of SEN Tribunal decisions on Lovaas style programmes. A legal industry has developed around these cases and fear of litigation often seems to inhibit free and open debate about Lovaas-style programmes. One legal representative has claimed a success rate of tribunals found in the favour of parents, of 100 to 9. These cases, however, often involve expensive witness costs and parents have informed the project that the personal costs to them range from £4,000 to £8,000 per case with no guarantee that they will succeed. It is of concern that families often feel pressured to take out personal loans to finance what they believe is a necessary intervention for their child.

2. Terms of Reference

To analyse existing programmes used to support children with autism: Lovaas, Son-Rise Option, etc.

3. Methodology

Consultative research has been an overarching principle of the methodology employed in every aspect of the West Midlands Regional Co-ordination Project. In order to “analyse existing programmes used to support children with autism: Lovaas, Son-Rise Option, etc”, it was important to identify a means of consulting all ‘stakeholders’. Stakeholders included Carers, Educational Psychologists and LEA Officers.

Carers’ Views were sought through the Carers’ Questionnaire, which provided a comprehensive overview of family experiences within the West Midlands, and through direct discussion with several families. The project was also privileged to receive significant support from Parents for the Early intervention of Autism in Children (PEACH) and Parents Autism Campaign for Education (PACE).

Professionals’ Views were sought through a workshop, which aimed to:

- ◆ Share views and experiences in the monitoring and evaluation of current LEA funded programmes
- ◆ Consider issues arising from differential funding/costs
- ◆ Discuss the legal implications of the wording of statements; insurance; health and safety issues
- ◆ Consider contractual agreements with parents/therapists/providers
- ◆ Consider SEN Tribunal outcomes within the West Midlands

Following the workshop, the Project Management Team commissioned a working group to look at the issue of evaluation and monitoring of existing and future programmes.

4. Summary and Key Recommendations

Requests for home-based programmes within the West Midlands is a relatively new phenomenon compared with many other parts of the country where they have become firmly established within a range of provision e.g. Cheshire and Manchester. The project was, therefore, set the task of “analysing existing programmes used to support children with autism: Lovaas, Option Son-Rise, etc”.

As part of this analysis, an Evaluation and Monitoring Working Party was commissioned to respond to the need to ensure consistency in monitoring and evaluation techniques across the region. The Working Party has produced Regional Protocols on Monitoring and Evaluation, and a Recommended Operational Guide for LEAs who are responsible for the funding, implementation, monitoring and provision of home-based programmes.

Main Findings

- Over half of the 14 West Midlands LEAs have children following home-based programmes such as Lovaas or Option (9/14 authorities as at June 2000). Of those nine authorities, eight LEAs are funding the programmes.
- Many authorities have invested significant sums of money in ABA/Lovaas type programmes.
- There is a diversity of funding sources which underlines the inequity in decision making throughout the region.
- It is also evident that even when programmes receive funding from LEAs, the responsibility for implementation often rests with the parents. However, all families felt confident that the programme met their child’s need.

- Only eight (44%) of the eighteen programmes described by parents in the Carers' Questionnaire returns, were receiving professional support.
- Ten (55%) of the programmes receive no input from health or local authorities.
- There is a general consensus that early intervention in the form of home-based programmes can be a positive way forward in both aiding the individual child's development and in the 'skilling up' of parents in terms of understanding and supporting their child. However, the content, quality, ownership and costs of many home-based programmes leave continuing cause for concern.
- LEAs have to consider the equal opportunities issues that arise from differential costs in provision. For example, a part-time nursery placement (£1000 pa circa) compared to a Lovaas type programme, which can range from £7,500 to £24,000 plus per annum.
- Agreement by West Midlands LEAs to support home-based programmes has, without exception, been on a pilot basis. No Authority has been convinced that the intervention is entirely appropriate. Some LEAs have agreed to home-based programmes because of a lack of confidence in their existing pre-school provision, but have expressed concerns about their ability to monitor and evaluate the programmes.
- There appears to be a high level of support from professionals to consider alternative forms of intervention e.g. the National Autistic Society's Early Bird Programme.
- In some West Midlands Authorities, an attempt is already being made to increase the practical support families receive after their child's needs have been identified as being on the autistic spectrum through funding staff to implement the Early Bird Programme.

Key Recommendations

The Monitoring and Evaluation Group recommends to those authorities that do decide to adopt a home-based approach to early intervention that:

- they identify a clear pathway which will support the child's progress into a continuum of provision
- programmes should be part of an overall plan and should not be set up in isolation
- consideration should be given to the use of Learning Support Assistants in terms of training, employment and creative support e.g. supporting an integration programme into pre-school provision at stage 3 of the current Code of Practice
- the transition programme should be driven by and built around, the child's Individual Education Programme (IEP). The IEP should be drawn up by the LEA in collaboration with the parents and therapists
- authorities should challenge the need to obtain a 'diagnosis' before children have an entitlement to pre-school support, especially when professionals support the intervention as being in the best interests of the child. Many early intervention programmes can appropriately focus on a range of communication difficulties that are not necessarily ASD specific
- integration programmes should be planned to cascade newly acquired knowledge and skills throughout the school
- multi-agency links should be established to ensure that all agencies are aware of the programmes and play an appropriate part
- before any programmes are agreed, professionals must be reassured that families have made an informed choice based on early and accurate information about available provision and anticipated outcomes

- families should enter a contract with the funding authority, which specifies methodology, responsibilities and the processes for transferring to maintained school provision and evaluating and monitoring progress
- there is a need to differentiate between home-based programmes and education otherwise
- there is a need to build in a requirement to seek a view from social services on the likely impact the programme will have on the family and whether the working environment is suitable for both the child and the therapists
- the programme objectives should be aimed towards National Curriculum requirements, Early Learning Goals and Foundation Stage Curriculum delivery
- for those authorities that support families using relatively short, intensive programmes such as Early Bird, further discussion within the region needs to take place to ensure that family support is continued after the completion of the 3-month programme. It is suggested that trained Learning Support Assistants (LSAs) are employed to continue the support to the families until critical targets (such as those agreed by the regional Monitoring and Evaluation Group), have been reached. The LSA would then act as a link with nursery/school staff as the child transferred from home to nursery/school. Ideally this role would be in a multi-agency context, to ensure that the family have continuity in terms of health, social services and educational input.
- data collection would be required to evaluate the effectiveness of the approach described above. Results should be fed back to the Monitoring and Evaluation Group as part of a regional remit of monitoring and evaluating home-based programmes.

5. Home-based Programmes – background information

Definition of ‘home-based programmes’.

For the purposes of this report, the term ‘home-based programmes’ describes the more unconventional, controversial programmes of intervention, that are commonly delivered within the home environment. These include Applied Behavioural Analysis (ABA)/Lovaas and Son-Rise Option programmes. Home-based programmes such as Portage are not considered as they are commonly included as part of the long-established pre-school provision in many authorities. Portage is well developed and researched and there is less controversy about children and families being supported using these programmes.

Background

Lovaas/ABA Programmes

The Lovaas programme is based on applied behavioural analysis (ABA) principles and involves intensive 1:1 discrete trial training for up to 40 hours per week. Parents and other adult helpers/therapists share the delivery of the programme. The programme is designed to deliver early intervention for young children (i.e. pre-school).

There have been many reviews and debates about the effectiveness of early intensive programmes, starting with the publication of the study by Lovaas in 1987; ‘The Young Autism Project’ (Lovaas, 1987)

Lovaas studied 3 groups of children with autism, all under 4 years old. The experimental group of 19 children received 40 hours of 1:1 therapy per week for 2 years. A control group of 19 children received 10 hours plus, of 1:1 therapy per week for 2 years and a second control group of 21 children, received no special treatment.

Lovaas' results showed that by age 7 years, 9 out of the 19 children (47%) had improved so much they were regarded as 'normal functioning'. It was claimed they had shown 'recovery', i.e. they were successfully placed within mainstream school, gaining IQ scores of average or better. At 13 years of age it was claimed that 9 of experimental group were still showing improvements. The children in the Control groups showed no improvements.

Controversy has continued since Lovaas wrote this paper, with calls for further research into the programmes' effectiveness (e.g. Gresham and MacMillan, 1997). Gresham and MacMillan argue that there is no empirical evidence to demonstrate that the intensive ABA programmes are effective with children with severe or profound learning difficulties, as the original children in Lovaas' studies were higher functioning than this. They also query if the programmes will be so effective when the parents and therapists are living and working many miles from the specialist teams and are not able to participate in the high level of initial training which took place in the original studies. Family commitment, time and ability to deliver the programmes will all also affect the outcomes of the programmes, as will the ability and commitment of the therapists.

Further studies conclude that for any intensive behavioural programme to be effective there should be:

- active involvement of parents/carers
- an interdisciplinary approach
- precisely applied teaching methods
- clearly stated objectives
- a high level of structure
- individualisation of programme elements
- intervention which starts early

(See Birnbrauer and Leach, 1993 and Dawson and Osterling, 1997)

Individualising the programme elements is extremely important. Autism is a disorder that affects a wide spectrum of individuals, whose needs differ in type and severity. Programme elements may need to be adapted and reviewed as a function of a child's age and level of development (Campbell et al 1996).

Son-Rise Option

The Son-Rise Option Institute states that their programmes are all individualised. They believe the most effective way to 'teach' children, young people and adults is to draw information, understanding and insight from them, and to develop and build on their talents, skills and interests' (The Option Institute and Fellowship, 1997). Parents/carers are taught to accept the child and all their behaviours. Instead of trying to push them to conform to society's priorities, parents/therapists attempt to form a bond with the child that is so exciting, the child will want to know more and learn more from those around him. The programme is built around the 3 'Es', namely excitement, enthusiasm and energy.

A week-long training programme called 'The Son-Rise Program Start-Up' was created to teach families and professionals the basic techniques to begin a home-based programme. For many families in England, however, this will involve the expense of travelling to America for training and the waiting list for the Option Institute is currently at least 2 years.

The Option programmes are of a similar intensity to the ABA/Lovaas programmes and are ideally carried out in a specially designed playroom. This helps to create a distraction free environment where the child can learn. The main difference between ABA/Lovaas and Son-Rise Option is that in the former approach, the child is taught pre-determined skills, whereas the Option approach takes the lead from the child. Recent critiques of both the Option and ABA approaches, however, suggest that in practice, these approaches may converge as programmes are modified to suit individual circumstances and learning styles.

Pre-school Programmes - General

Dawson and Osterling (1997) compared the progress of 24 children in eight different approaches and found that nearly all the children were reported to have made significant gains. Although the conclusions are not so meaningful because of the lack of control groups, Dawson and Osterling (cited in Connor, 1998) did identify a useful list of elements which they concluded are essential for a pre-school programme:

1. *Curriculum content*

Five basic skills should be emphasised – the ability to attend, to imitate others, to comprehend and use language, to play appropriately with toys, and to interact socially with others.

2. *Supportive teaching settings and generalisation strategies*

A typical pattern involves teaching skills via intensive methods with subsequent attempts to elicit those skills among other people or in other settings.

3. *Predictability and routine*

The child with autism appears highly sensitive to any changes in the environment and disruption to behaviour and progress will be avoided when stimulation is offered in a predictable manner. There is a need for structure and for preparing the child for impending changes.

4. *Functional approach to problem behaviour*

Again, the implication is for a firm structure and for increasing motivation via reinforcement for classroom activities and communication skills.

5. *Transition from the pre-school setting*

One prepares the child to function as independently as possible.

Powers (1992) lists the following as critical elements for independence:

- ◆ compliance with requests;
- ◆ turn taking;
- ◆ listening to directions from any source;
- ◆ sitting quietly during activities;
- ◆ volunteering; raising a hand to gain attention; picking up toys after use; communicating basic needs;
- ◆ toileting.

Pre-school staff should also visit the proposed class to determine which skills are to be practised.

6. *Family involvement*

Parents spend more time than anyone else with their children and are in a position to recognise, and act upon, their needs. Further, by the involvement of parents in training, there is greater probability of maintaining and generalising the skills in the children. Parents will feel more empathy with their child and a greater sense of their own competence.

7. *Intensity*

All the programmes involve many hours of activity each week. One programme (the LEAP programme) requires at least 15 hours, and all the others require 20 or more.

Dawson and Osterling conclude that further studies are required to directly compare the effectiveness of various programmes but **what does appear to be a key in many of the approaches used with children with an ASD, is early intervention.**

6. Implications for ABA/Option Programmes in the Region

Professionals and parents/carers have become bewildered as to which approach should be used with children with an autistic spectrum disorder (ASD). In 1998, the DfEE commissioned a team from the University of Birmingham to “set out what is known about educational interventions with children with an ASD and to discover what gaps exist in our knowledge”. Jordan, Jones and Murray looked at interactive approaches, approaches to communication, integration approaches, Division TEACCH, Daily Life Therapy as practiced by the Boston Higashi School and behavioural approaches. Their research concluded, however, that there was ‘no really strong evidence to suggest that one approach for a child with ASD is better than another’ (Jordan, Jones and Murray, 1998).

The summary above demonstrates that there is still no agreement as to the effectiveness of any approaches with children with an ASD, let alone home-based programmes. It is clear, however, that early intervention (i.e. 3 – 4 years old) can be effective in minimising the future level of special needs support necessary in the child’s school years and adult life. What type of intervention works for any particular child is not clear, every child and family is different and decisions about any input should be made on an individual basis. The age of the child, their developmental level, the child’s family circumstances, (e.g. the level of involvement of the parents/carers) should all be taken into account. The intensity of an ABA programme will not suit every family or every child. Significant levels of concern have been expressed by many professionals with regard to the amount of one-to-one adult directed activities a young child is expected to comply with, in an intensive ABA programme.

It is also argued that social interactions with peers and siblings are necessary for social and cognitive development (Dunn, 1984) but that intensive one-to-one adult intervention does not allow for this. Counter arguments to this state that children with an ASD need to be taught the skills of social interaction before they can socialise with peers and siblings. (Most other children learn the skills of social interaction from a very early age during the course of normal development).

Other concerns raised in debates about home-based programmes are the way parental expectations could be raised concerning 'recovery'. In his paper in 1987, Lovaas talks about 'recovery' from autism, meaning the children were indistinguishable from other children without autism. This has led to the notion that the children taking part in an intensive programme such as Lovaas will progress so that they no longer have an ASD; they have 'recovered'. If children do not make the expected gains, however, then this notion of 'recovery' may put undue pressure on parent/carers. They may then blame themselves (for failing to meet the demands of the programme), the LEA (in failing to provide enough funding or support) or even the child. (Selfe, 1998). The suitability of the programme itself is not usually questioned, often because of the intense amount of emotional and physical energy that has been invested in following it. Whilst it is clear that parents need hope and a positive outlook on their child's progress, it is important that they do not become disillusioned if their child still shows continued difficulties within the triad of impairments. Professional support in setting individualised, realistic targets is vital in any home-based programme.

In an ideal world, parents would be given the opportunity to make well-informed choices, in partnership with the professionals from the different agencies, about the intervention they choose for their child with autism. The intervention chosen should take into account the individual child's learning style and the type of programme the family feel comfortable with. There should be clearly agreed targets in order to measure progress and agreed criteria for when the programme ceases and the child integrates into full-time schooling.

The key to success of the example cited above, is 'choice'. Very often parents/carers choose the path of home-based programmes such as ABA/ Lovaas/Option because there appears to be little on offer for their pre-school child with autism or LEAs have failed to 'market' their provision. It is vital that this issue is addressed and that support in terms of information and advice is provided to families throughout and after, the assessment and identification process. Parents/carers want and need training on how to work with and understand their children with an autistic spectrum disorder.

7. Levels of Parental Satisfaction with Home-based Programmes

A large survey of families (Carers' Questionnaire) was carried out within the West Midlands in the Spring Term of 2000. The project received responses from eighteen families who had chosen to follow a home-based programme for their child. Sixteen of these families were following Son-Rise Option/ABA/Lovaas programmes.

Table to show distribution of home-based programmes:

Name of Programme	Frequency
Pre-school home teaching	1
Son-Rise Option	2
ABA	1
Lovaas	13
Portage	1
Total	18

The following table illustrates the diversity of funding sources and underlines the inequity in decision making throughout the region.

Funding Source	Frequency
LEA	10
Health	1
LEA and private	1
Parents - includes fundraising and personal loan	6
Total	18

It was also evident that even when programmes received funding from LEAs, the responsibility for implementation often rested with the parents.

Name of Programme:	Implemented by:	Frequency:
Lovaas	LEA	8
Lovaas	Parents	5
Son Rise Option	Parents	1
Pre-school home teaching	LEA	1
Son Rise Option	LEA & Private	1
ABA	LEA	1
Portage	Health	1

However, all families felt confident that the programme met their child's needs. One family mentioned 'a need to expand' and another commented, "yes it meets my child's needs but socialisation is missing".

It is a matter of concern, that when asked if they "have help from any professionals – e.g. educational psychologist, specialist teacher, speech and language therapist", that 8 families responded 'yes' but 10 families responded 'no'.

An analysis of responses shows that:

- Only eight (44%) of the eighteen programmes were receiving professional support in the form of input to programmes or monitoring visits
- Pre-school and Portage programmes are supported by specialist teams
- One Son-Rise Option programme is supported by an educational psychologist, speech and language therapist and a nurse
- Four Lovaas programmes and the ABA programme received support from a speech and language therapist and three Lovaas programmes were supported by an educational psychologist
- Ten (55%) of programmes receive no input from health or local authorities.

8. The Way Forward

If there was a greater choice of provision in an LEA, then it would be possible to 'produce a greater match between the child's needs, the context in terms of familial resources and attitudes, and the programme content' (Connor, 1998).

In some West Midlands Authorities, an attempt is already being made to increase the practical support families receive after their child's needs have been identified as being on the autistic spectrum.

Examples of Good Practice:

Warwickshire, Solihull, and Coventry have funded staff to attend the National Autistic Society's Early Bird Programme. The Early Bird Programme states that its aims are to:

- ◆ support parents in the period between diagnosis and school placement
- ◆ empower parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment
- ◆ help parents establish good practice in handling their child at an early age so as to pre-empt the development of inappropriate behaviours (Early Bird Centre, 1999)

The framework of the programme is taken from the Hanen Programme which has been developed to help parents encourage their child's communication development. Early Bird, however, is autism specific and draws much of its content from the National Autistic Society's SPELL approach, techniques from Division TEACCH and the Picture Exchange Communication System (PECS).

The programme requires a team of at least two professionals with an experience of autism, who work with a group of 6 families. Families take part in regular (weekly) training sessions and video feedback. Each programme lasts for 3 months.

Leicestershire is one of the pilot authorities evaluating the Early Bird programme, which has been jointly funded by Health and Education (see appendix 6 for approximate costings). The Educational Psychologist who has responsibility for managing the programmes reported that early indications suggest that the programmes have been extremely successful – it has focussed parents on being interactive with their children and has given them emotional as well as practical support. **Requests for intensive programmes such as ABA/ Lovaas have decreased.**

9. The Regional Picture

Over half of the 14 West Midlands LEAs have children following home-based programmes such as Lovaas or Option (9/14 authorities as at June 2000). Of those nine authorities, eight LEAs are funding the programmes. Three of the remaining five authorities have had requests for home-based programmes; one authority has had no requests as yet but feels this is likely to change. One authority has been involved in a tribunal where the case was dismissed.

An Audit of the programmes within the West Midlands region revealed the following:

Birmingham: At the time of writing, there are three children following home-based programmes such as Lovaas or Option in Birmingham. A further request has been received.

Coventry: There are six children on LEA funded Lovaas programmes, all at Stage 5 of the Code of Practice. The LEA requests that the parents fund the programme for the first six months as evidence of their commitment to the programme. A condition of funding is that the parents agree that the primary aim of the programme is to enable their child to enter primary school provision when they reach compulsory school age. The programmes are funded on a pilot project basis; the EPS and Autism Support Service have been asked to monitor and evaluate the programmes.

Dudley: is funding one Option programme.

Herefordshire: There have been no requests for Lovaas or Option within Herefordshire.

Sandwell: There have been no requests for any home-based programmes to date.

Shropshire: One child who was educated at home through a privately funded Lovaas programme has now reached compulsory school age and the LEA has taken over funding.

Solihull: Solihull is currently supporting two programmes. One of children previously attended the Higashi School in Boston, America. Another family has appealed to the SEN Tribunal.

Staffordshire: Staffordshire is supporting four families on home-based programmes. Two are following Lovaas; one is following an Option programme and one a 'home-grown' programme. The EPS has responsibility for monitoring the programmes.

Stoke-on-Trent: As a consequence of a recent SEN Tribunal decision, Stoke-on-Trent is currently supporting one family who are following a Lovaas programme. One family is self-funding an Option programme.

Telford and Wrekin: Telford and Wrekin are supporting one family on an Option programme.

Walsall: The LEA is tracking one Lovaas programme.

Warwickshire: There are four families following Lovaas programmes, funded by the LEA. One family is following an Option programme. The EPS and Speech and Language Therapy Service jointly monitor the programmes.

Wolverhampton: Wolverhampton has had no requests for home-based programmes.

Worcestershire: There are no LEA supported Lovaas or Option programmes within Worcestershire. Hereford and Worcester successfully defended a decision not to support a Lovaas programme at an SEN Tribunal hearing.

10. Evaluation and Monitoring Arrangements for Home-based Programmes

Agreement by West Midlands LEAs to support home-based programmes has, without exception, been on a pilot basis. No Authority has been convinced that the intervention is entirely appropriate. Some LEAs have agreed to home-based programmes because of a lack of confidence in their existing pre-school provision but have expressed concerns about their ability to monitor and evaluate the programmes.

The Project Management Team formally commissioned an Evaluation and Monitoring working party to respond to the need to ensure consistency in monitoring and evaluation techniques across the West Midlands. The group is facilitated by the West Midlands Regional Co-ordination Project and consists of LEA Educational Psychologists and representation from the University of Birmingham.

Terms of Reference

After much intensive discussion, the group set themselves the following remit

- To complete a full audit of current cases, which includes details on programme type, cost and the age and gender of the children involved
- To collect background information on alternative provision within each authority. It was felt that provision might be an important factor when analysing the reasons why parents are requesting home-based programmes and LEAs are making different responses in terms of agreement to and funding of programmes
- To agree definitions
- To agree ways to collect and collate data to facilitate comparisons between cases and between authorities
- To agree how and when children should integrate into full-time schooling and provide a process to be followed
- To clarify what it is that is being monitored
- To clarify who the monitoring is for
- To clarify the purpose of monitoring/evaluation
- To distinguish between monitoring and evaluation
- To identify who was best placed to monitor and evaluate the programmes - should it be EPs?
- To consider resource constraints, how much time will LEAs be able to give to EPs for monitoring the programmes?
- To identify the scope for joint target setting between therapists, parents and LEA.

Outcomes

Definition of Monitoring and Evaluation

'Monitoring' is the process of gathering information over time, 'evaluation' is interpreting the information and establishing it's worth i.e. is the programme working? Is it delivering what it set out to do? The process should be a cyclical one; plan, monitor, evaluate, plan, monitor, evaluate.

Evaluation should be cumulative and always have the purpose of moving something forward. A child's review could be seen as part of the evaluation process. A baseline should always be established so that achievements can be determined.

Assessment information required

After much debate the group decided that the following information should be collected for each home-based programme that was already running in the authority and subsequently for any new programmes:

- Background History: Diagnosis details – dates, by whom, evidence base? Additional descriptors?
- A Pupil profile: strengths and difficulties in the following areas – *Communication and Language, Play skills, Behaviour, Social Skills and Social Understanding, Intellectual Functioning, Severity of Autism, Daily Living Skills, Anxiety Levels, Fine and Gross Motor Skills, Attainment, Learning Styles, Sensory.*
- A Speech and Language Therapy report
- Observations in a variety of settings (video if possible)
- Teaching Talking Profile
- Childhood Autism Rating Scales (CARS)
- Vineland (Parent and key staff interview)
- Description of time-limited goals shared between parents/carers and the LEA.

Other data/information that should be collected

- Timetable of programme delivery including personnel involved. (Details of the timetable should include hours spent on the programme per week, plus number of weeks per year if known. Missed sessions, due to illness/turn over of therapists, for example, should also be recorded)
- Description of learning environment
- Details of any other interventions/programmes being provided (including diet and sensory interventions)
- Impact on family including information on sibling interactions, work done with other family members e.g. grandparents
- Costs involved
- Plans for transfer of the programme into the school setting

Frequency of monitoring

Programmes should be monitored at least once per term. Time spent monitoring the programmes should be logged.

Input from Speech and Language Therapy

Ideally there should be joint-working - joint home/school visits

Nursery /school placements

A shared understanding between parents, helpers and professionals should be made as early as possible concerning the timing and nature of the provision to follow the home-based programme. It should be made clear to all that Nursery/school placements are not to be just another venue for one to one drills. A major benefit of nursery/school placements is social interaction.

Nursery/school transfer

The family will require access to a neighbourhood nursery/school. Home-programmes should include targeting the skills needed to link into school/nursery so that the child can function as independently as possible. These will include:

- ◆ Peer interaction
- ◆ Observing other children
- ◆ Turn taking

Other critical elements for independence – listening to directions from any source; sitting quietly during activities; volunteering; raising a hand to gain attention; picking up toys after use; communicating basic needs; toileting (Powers, 1992)

There should be an activity analysis for each individual setting at the nursery/school. Expectations of the child should be made explicit. For example, it may be a necessary skill that the child is able to sit on the carpet, is able to answer the register, is able to respond appropriately to adult commands etc. Language used within the nursery setting should be analysed and careful thought given to the receptive/expressive vocabulary needed.

Targets in the home-based programme should be shaped so that they are relevant to the next setting, e.g. nursery/school.

11. Should Authorities Support Home-based Programmes?

There is a general consensus that early intervention in the form of home-based programmes can be a positive way forward in both aiding the individual child's development and in the 'skilling up' of parents in terms of understanding and supporting their child. However, the content, quality, ownership and costs of these programmes leave continuing cause for concern. LEAs also have to consider the equal opportunities issues that arise from differential costs in provision. For example, a part-time nursery placement (£1000 pa circa) compared to a Lovaas type programme, which can range from £7,500 to £24,000 plus per annum.

There appears to be a high level of support from professionals to consider alternative forms of intervention e.g. the NAS, Early Bird Programme. However, further discussion within the region needs to take place to ensure that family support is continued after the completion of the 3-month programme. It is suggested that trained Learning Support Assistants (LSAs) are employed to continue the support to the families until critical targets (such as those agreed by the regional Monitoring and Evaluation Group), have been reached. The LSA would then act as a link with nursery/school staff as the child transferred from home to nursery/school. Ideally this role would be in a multi-agency context, to ensure that the family have continuity in terms of health, social services and educational input.

Data collection would be required to evaluate the effectiveness of this approach. Results should be fed back to the Monitoring and Evaluation Group as part of a regional remit of monitoring and evaluating home-based programmes.

The Monitoring and Evaluation Group recommends to those authorities that do decide to adopt a home-based approach to early intervention that:

- ◆ they identify a clear pathway which will support the child's progress into a continuum of provision
- ◆ programmes should be part of an overall plan and should not be set up in isolation

- ◆ consideration should be given to the use of Learning Support Assistants in terms of training, employment and creative support e.g. supporting an integration programme into pre-school provision at stage 3 of the current Code of Practice
- ◆ the transition programme should be driven by and built around, the child's individual education programme. The IEP should be drawn up by the LEA in collaboration with the parents and therapists
- ◆ authorities should challenge the need to obtain a 'diagnosis' before children have an entitlement to pre-school support, especially when professionals support the intervention as being in the best interests of the child
- ◆ integration programmes should be planned to cascade newly acquired knowledge and skills throughout the school
- ◆ multi-agency links should be established to ensure that all agencies are aware of the programmes and play an appropriate part
- ◆ before any programmes are agreed, professionals must be reassured that families have made an informed choice based on early and accurate information about available provision and anticipated outcomes
- ◆ families should enter a contract with the funding authority, which specifies methodology, responsibilities and the processes for transferring to maintained school provision and evaluating and monitoring progress
- ◆ there is a need to differentiate between home-based programmes and education otherwise
- ◆ there is a need to build in a requirement to seek a view from social services on the likely impact the programme will have on the family and whether the working environment is suitable for both the child and the therapists
- ◆ the programme objectives should be should be aimed towards National Curriculum requirements, Early Learning Goals and Foundation Stage Curriculum delivery.

12. Process recommendations

The Monitoring and Evaluation Group has produced a recommended Operational Guide for LEAs who are responsible for the funding, implementation, monitoring and provision of home-based programmes.

1. Introduction

Legal advice has confirmed that in principle, there is no difficulty with an LEA making provision for therapy at home where it considers that it is the appropriate course of action. However, this is based upon the assumption that the therapy equates to either educational provision or non-educational provision that has been specified in a statement of special educational needs. Sections 19, 319 and 324 of the Education Act 1996 are the material provisions.

In effect, this means that the LEA should determine how much therapy needs to be purchased, and then in consultation with the parents decide precisely when, how and by whom the provision ought to be delivered. An LEA might conclude that the parents can draw up the programme, but the LEA still has a legal duty to approve it. It should be remembered that the LEA is not empowered to delegate to parents what is ultimately its own discretion about what education should be provided.

2. Duties to arrange, monitor and review provision

The LEA's duty to arrange, monitor and review the provision for those children who are receiving tuition at a base other than a school, cannot be delegated. Even if the child is being educated at parental expense and the LEA is satisfied that the provision meets the child's needs, the LEA must still make arrangements to monitor the provision under 'education otherwise' and arrange the Annual Review of the statement.

In instances where the LEA is the funding body, it is crucial that the LEA takes ownership of the home-based programme. This will enable the LEA to maintain control and meet its statutory duties. These duties are specified in The Code of Practice on the Identification and Assessment of Special Educational Needs (CoP).

It is recommended that specific reference is made to the following sections in the CoP, when negotiating a home-based programme with parents.

Section 4 – deals with the Statement of Special Educational Needs

Section 4:28 – deals with the writing of the statement. It specifies that Part 3 of the statement is divided into three sub-sections as follows:

***Sect 1:** In the first section, the LEA should set out the main educational and developmental objectives to be achieved by the special provision over the expected duration of the statement. The second section should set out all of the special educational provision that the LEA considers appropriate for all of the learning difficulties identified in part 2 ...The LEA will be responsible for arranging all the special educational provision specified in the statement. This sub-section should also specify in accordance with section 18 of the Education Reform Act, 1988 any modifications or disapplications of the provisions of the National Curriculum (in terms of attainment targets, programmes of study and assessment arrangements) which the LEA consider necessary to meet the child's special educational needs.*

In summary: this can provide a non-negotiable basis on which to take and maintain control of the child's special educational provision and to ensure that the programme aims to meet the requirements of the National Curriculum, including the new Foundation Stage Curriculum.

The financial costs to LEAs of home-based programmes varies considerably across the region from between £7,500 to £18,750 p.a. (see appendix hb1). This financial variance is a common feature of home-based programmes nationally, with some programmes rising to above £20,000 p.a. When agreeing a child's provision, the LEA has a duty under Sect 4:40 of the CoP to consider whether:

- ◆ the placement (provision) is appropriate to the child's needs
- ◆ the placement (provision) is compatible with the interests of other children
- ◆ the placement (provision) represents an efficient use of resources

It is of note that there is only one reference to home-based programmes in the CoP. This is in Section 5 – Assessments and Statements for Under Fives:

Sect 5:23 – *Special educational provision for children under 5 acknowledges that for very young children, access to a home-based learning programme may provide the most appropriate help.*

This infers an assumption that by the time a child has reached compulsory school age (the term following their 5th birthday), the programme should have run its course i.e. for children of 5+ years, the forward option should be educational provision within a school.

Sect 5:24 goes on to say that:

“All services working within a local authority with young children should have clearly articulated arrangements for access to their services. These arrangements should be readily understandable by parents of children with special needs, indicate the kind of support which can be provided; and state any priority admission arrangements for such children.”

It can therefore be argued that provision made for children over the age of 5, constitutes home tuition, rather than education otherwise.

Review of the Statement where a child does not attend school

The monitoring of home-based programmes falls under Education (Special Educational Needs) Regulations 1994 17 – (1) to (10)). The LEA's duties are explained in Section 6 of the CoP, which deals with the Annual Review. Once again, this provides the LEA with an opportunity to assert its ownership by managing the programmes. It is evident that the responsibility for convening and chairing the annual review, and taking action following the review meeting, remains with the LEA.

Sect 6:24 – *The Annual Review for children with statements whose education is otherwise than at school, specifies that when a child is educated otherwise than at school, the general timetable and other arrangements for the annual review will remain the same as for children in schools. However, in these circumstances the LEA will convene the review meeting The review meeting should take place in the most appropriate location, such as the LEA's offices and should normally be chaired by the LEA.*

For some authorities, time constraints will mean that the totality of monitoring and evaluation will be centred on the annual review process. However, if the monitoring and evaluation process is to be taken seriously and be helpful in informing LEAs of outcomes, the issue of ensuring professionals have the time to fulfil the function of advisor, trainer and negotiator needs to be addressed.

Sect 6:27 – Actions following Annual Reviews

“Following the annual review the LEA must prepare a report which summarises the outcomes of the review meeting and sets out any educational targets for the coming year. The LEA must then review the statement, in the light of the review report and of any other information they consider relevant.

A review meeting may recommend amendments to a statement if:

Significant new needs have emerged which are not recorded in the statement

Significant needs, which are recorded on the statement, are no longer present

The provision should be amended to meet the child's changing needs and the targets specified at the review meeting or

The child should change schools, either at the point of transfer between school phases for exampleby integration”.

The IEP also provides a tool for monitoring and should therefore become a requirement when negotiating a home-based programme with parents. IEP review meetings are commonly recommended to take place on a termly basis. The CoP sect 2:119, stipulates that IEPs should include written information about:

- ◆ individual programmes of work
- ◆ performance targets
- ◆ review dates, findings and decisions
- ◆ parental involvement in and support for the plans
- ◆ arrangements for the involvement of the child
- ◆ information on any external advice or support

Issues

Programmes that are already in place without clear agreements between the LEA and the parents are proving difficult to review by the professionals involved. In order to regain the 'ownership' of the programme and establish a clear pathway to full integration within a school environment, professionals (Educational Psychologists, Support Teachers and LEA Officers) have to be given a clear mandate to manage the review of the programmes.

Recommendations

Implementation and monitoring of the programme and review of the Statement of Special Educational Needs should include:

- ◆ An initial visit to negotiate the terms of the current programmes and make clear the need for and the process of monitoring and review.

- ◆ A termly review of the IEP - the first IEP should include the name of the parental preference for a school, to reinforce that the programme's primary aim is to achieve full integration into school. The named school should be informed of the parents' preference and kept informed of the child's progress and anticipated admission date.

- ◆ An Education Otherwise visit for school aged children – which will focus on the requirements of the National Curriculum (in instances where the LEA is not funding the programme).

- ◆ A full planning meeting before entry to school, to plan the transition. This should include relevant school staff.

- ◆ Annual review meetings to be planned well in advance. The meeting should be convened and chaired by the LEA and the proposed school should be represented.

Planning the integration programme

It is difficult to prescribe a process for transition, because it will inevitably demand an individualised focus on collaboration, negotiation and working together as responsibilities shift. The Monitoring and Evaluation Group therefore suggest that in reaching an agreement on an integration programme, the following issues/questions need to be addressed in order to achieve the desired outcomes. (For an additional model see appendix hb5).

1. Who has ownership of the IEP in terms of the writing, delivery and monitoring?

Initially the responsibility rests with the LEA and not the parent. This will pass to the SENCO, effectively when the child is on the roll of the school i.e. attending on a 0.5 basis. The exact transfer of responsibility needs to be negotiated and a specific date set.

2. Who has the management responsibility for the child during integration? Is it the Headteacher, governors, class-teacher, LEA or parents and/or therapists?

On a day-to-day basis, the Headteacher or SENCO of the receiving school will increasingly share responsibility for the child with the supervisor of the home-based programme. When the child is physically in class, the child's class-teacher will be responsible and have authority over any home tutor who is present. Responsibility for the child's education should transfer completely to the school at the point the child is placed on roll and ideally in an age appropriate class.

3. Who manages any training issues?

Training in 'Autism awareness' should be delivered by the LEA to all staff involved in the child's integration programme. Training could and maybe should include the child's parents. If therapists are to be involved in training, this should be managed and supervised by the LEA. When a child transfers to the roll of the school it is assumed that any therapists who continue to be employed by the school, will take on the roll of learning support assistants and will, therefore, attend accredited courses.

4. Does the programme comply with the legal framework of the National Curriculum?

It is crucial from the outset, but increasingly over time, that programmes should be linked systematically to the curriculum of the future school in order to facilitate the integration process. This will assist the generalisation of the programme within the classroom environment thereby complementing the classroom provision and enabling access to the Curriculum.

5. Should it be assumed that the current therapist will work within the school?

Ownership of the employment issues will transfer to the Governing Body of the receiving school. It should not, therefore be assumed that the school will automatically employ the current therapist/s. Indeed, equal opportunity issues may demand that the posts are evaluated and advertised in accordance with normal recruitment procedures. It will also be necessary to review the employment contract in terms of salary (to comply with single status) and changing working conditions. The contract will have to reflect an expectation that there will be a progressive reduction in hours, as the child becomes a more inclusive member of the class group.

6. What is the timetable for integration?

The timetable should be optimistic and individually planned with clear goals relating to:

- a) time in school
- b) inclusion in specific activities including break-times and non-academic subjects
- c) identification of the stage/criteria at which the child will be placed on the roll of the receiving school.

7. Level of inclusion

This will link to the planned timetable. The child should be able to demonstrate a level of participation in school activities and secure arrangements should be in place to enable the child to be included within the class group.

The IEP should specifically address inclusion objectives as well as generalisation objectives relating to skills that would facilitate the inclusion process.

8. Legal compliance

All parties must be confident that the transition plan meets statutory requirements, which means that the home programme begins to address the National Curriculum, via objectives linked to the school's curriculum.

Section 4

Home-based programmes

Appendices

Appendix hb1

Rubric of Current Home-Based Programmes within the West Midlands

@ June 2000

Authority	Lovaas	Option	Cost
1. Birmingham	3	0	£37,500 est.
2. Coventry	6	0	£68,000
3. Dudley	0	1	£18,705
4. Herefordshire	0	0	Nil
5. Sandwell	0	0	Nil
6. Shropshire	1	0	£12,500 est.
7. Solihull	2	0	£30,000 est.
8. Staffordshire	3	1	£67,500 est.
9. Stoke-on-Trent	1	1	£25,000 est. Parents funding Option
10. Telford and Wrekin	0	1	£9,000 est.
11. Walsall	1	0	£17,500
12. Warwickshire	5	1	£75,000
13. Wolverhampton	0	0	Nil
14. Worcestershire	1	0	Nil
Totals	22	5	£361,038

Appendix hb2

The Legal Position for Funding Home-based Programmes

Nigel Giffin was instructed to advise Warwickshire County Council on the legality of funding Home-based programmes such as Lovaas. His opinion is as follows:

“The Council is a local education authority owing duties to children with special educational needs pursuant to the Education Act 1996.

Certain parents of children with special educational needs wish to meet those needs through home-based programmes, such as the Lovaas programme for autistic children. This may involve, for instance, professional therapists attending at the home. Can the council meet the cost of such provision, and (if so) how may it do so – for instance, may it make direct cash payments to the parents out of which to meet the costs? I am instructed that the Council’s present practice in cases in which it considers that such a programme is appropriate, is to allocate a fixed sum, which it then spends in such a manner as the parents decide (either by engaging directly the staff nominated by parents, or by reimbursing the parents for expenses they have incurred).

In principle, there is no difficulty with the Council making provision for therapy at home where it considers that it is the appropriate course or action, assuming that the nature of the therapy is such as to amount to educational provision (or if it is non-educational provision specified in a statement of special educational needs). Again, ss19, 319 and 324 of the Education Act 1996 are the material provisions. Therapy unconnected with education would be a matter to be dealt with under the Council’s social services functions in an appropriate case.

However, I have some reservations about the arrangements suggested for meeting these costs. There is clearly no objection to the Council deciding how much therapy needs to be purchased (see note 13), and then consulting with the parents about precisely when, how and by whom that allotted provision ought to be delivered. That could extend to the parents drawing up the programme, and the Council approving it. Further, there is clearly no reason why the parents and therapists should not arrange details such as the precise times at which home visits will take place without

reference to the Council. It would also be possible for the parents to act as the Council's agents in making payments to the therapists, if that was the most practical and convenient course (at the moment I have slight difficulty in seeing why it should be necessary).

But I do not think that the Council is empowered to delegate to the parents what is ultimately its own discretion about what education should be provided, i.e. simply to relinquish control to these parents. Still less do I think that the Council can simply hand over cash sums to the parents to be spent as they think fit (14), even upon the basis of a condition that the money has to be spent on a particular kind of therapy. The argument, that a power to "arrange" provision of goods or services of "make arrangements" for those goods or services to be provided empowers a local authority to hand over cash to the beneficiary to acquire goods or services himself, was advanced but rejected by the Court of Appeal in *R v Secretary of State for Health ex p. M and k1998* 1 CCLR 495 (cash payments to asylum seekers). The Community Care (Direct Payments) Act 1996 does not apply to educational functions."

Conclusion

The Council may provide home-based therapy as part of educational provision, but cannot simply hand over a budget or cash sums to parents.

(13) Although the starting-point must be what the child needs, not some arbitrary cash limit.

(14) Whether this happens in advance of the expenditure being made or by way of reimbursement is a matter of mechanics which does not affect the legal issue.

Appendix hb3

The Project Workshop on Home-based Programmes

The professionals' workshop held in September 1999, brought together a group of interested professionals to discuss the issues surrounding home-based programmes and to look at possible ways forward.

Summary of discussions

Pros and cons of home-based programmes (Lovaas and Option)

The following list is a summary of thoughts from the participants at the Project's workshop on home-based programmes. Home-based programmes were defined as ABA/Lovaas/Option. The pros and cons are described from three perspectives: the parents'/carers'; the child's; and the Local Education Authority's (LEA's).

Arguments for home-based programmes

Parents' perspective:

- There is a high level of parental involvement: which can lead to 'skilling up' for parents
- Enables parents to feel that they are contributing/have some control
- Makes a role for parents, empowers them in an otherwise disability.
- Great expectations are enabling; parents can see 'progress'
- Emotional support available

Child's:

- Early intervention
- Children like the structure
- 24hr continuity (or is this a con depending on quality?)

LEA's:

- Sharpens up LEA thinking on pre-school provision and their approaches to ASD
- Best value: responding to local parents
- The LEAs can have satisfied parents

- Can be cheaper than alternatives
- LEAs may have to fund at the moment to gather information for evaluation purposes.

Arguments against home-based programmes

Parents' perspective:

- there may be a huge impact on the family – siblings
- can cost families money, e.g. house sales
- intrusion
- parents feel a responsibility for the outcomes
- training parents – skills then not necessarily utilised with other children
- are miracle cures promised?

Child's:

- social isolation, children not experiencing normally developed children/lack of role models
- intensity, lack of opportunities for play/interaction with peers. What are the long-term effects of limited play in normal development?
- Lovaas is not autism specific
- moves total focus
- anti-inclusion
- overload on child if following programme in addition to attending school

LEA's:

- diverts funds from other developments
- extremely time consuming
- mainstream integration – formal process difficult to establish
- neither approach (ie Option/ Lovaas) has a time limit or exit criteria
- increases emphasis on conflict management – parents believe they have to fight
- equality of opportunity (how many children would qualify), inequality of provision; programmes may have a detrimental effect in terms of building up LEA provision: home-based programmes are only one arm of provision. Issues of equality for other children
- efficacy – is it appropriate for all?

- difficulties with early diagnosis – is the diagnosis correct?
- may be difficult to deliver the programme
- is Lovaas a consequence of the ‘what next syndrome’?
- lack of knowledge in individual LEAs
- concern about out of school provision
- under whose direction are the programmes? Parent, Head, Supervisor?
- problems related to evaluation
- lack of health service input
- transferable resources: notional savings

Outcomes from Discussion Group considering the question:

Should LEAs support home-based programmes?

There was a general consensus, that if the wider definition of ‘home-based programmes’ was used, then authorities would agree with them in principle. However, it was also felt that there was a need to separate delivery from methodology. **There was no general consensus on supporting home-based programmes such Lovaas and/or Option.**

Points made during the discussion groups: -

- ◆ If there is a general principle of supporting ‘home-based’ programmes in the wider sense to include for example, Portage, then how is it decided what is the best programme to follow?
- ◆ What can authorities offer? If there is pre-school provision which the parents can feel confident in, then would families be asking for ‘home-based programmes? Do parents lack confidence in the services on offer at the present time?
- ◆ Is there a need for support which helps to develop families’ skills in coping with their child with ASD along side any pre-school provision on offer?
- ◆ What are the cost-benefits to an LEA? Are home-based programmes cost effective?
- ◆ There is a need for good quality, eclectic provision
- ◆ The Lovaas programme is extremely intensive; it constitutes more than the average adult working week in terms of hours

- ◆ Are there any holistic benefits?
- ◆ What input should Health & SSD have?
- ◆ Once a programme is in action, should the LEA embrace and support it?
- ◆ Who employs the support workers? What training do they have? Who monitors and evaluates progress?
- ◆ Are there equal opportunity implications of supporting intensive home-based programmes?
- ◆ Are Authorities meeting the needs of the child or the family?
- ◆ Parents often make direct comparisons of 1:1 time allocated between nursery and a home-based programme; for example, Telford & Wrekin fund 25 hours = school week.
- ◆ **There is a need to evaluate.**

Summary of main issues:

- ◆ What is the LEA's general philosophy – do they support home-based programmes or not?
- ◆ What are the costs? Are home-based programmes cost-effective?
- ◆ Are there questions regarding equal opportunities to be addressed?
- ◆ How do we evaluate?

Appendix hb4

SEN Tribunals

Taking into account their collective experience, a workshop discussion group were tasked with making recommendations for the group on models of good practice for the preparation and presentation of SEN Tribunals in instances where an LEA had decided that it would be inappropriate to support a home-based programme.

It was assumed that the parents' arguments in support of their appeal were that:

- home-based programmes/intensive individual intervention have been proven to work
- that the LEA current/proposed provision was inadequate to meet need and
- the quoted costs of the programme are between £18,000 - £25,000 per annum.

Preparation

The following points arose from discussion:

Choice of witness: There is a need to think carefully about the choice of witness; it was generally agreed that you should seek the right person rather than the right designation. Tribunals responded well to professionals who had worked directly with the child. School staff would need to be ambassadors for their own provision. They have to have at their fingertips, details of staffing, group size, SEN budgets and additional/specialist qualifications of staff. Individuals should be able to present their case with confidence whilst balancing a sensitive approach to parents. Ideally this information should be included in the LEA's written submission.

Choice of representation: It was felt generally desirable that Authorities matched like with like i.e. if parents used a barrister then it would be appropriate for the LEA to do likewise. A tribunal might look unfavourably upon an LEA who was represented legally, if a parent was not.

Officer representation: Where LEAs had sacrificed officer representation to allow for a Barrister plus 2 witnesses, they felt penalised because the Barrister would not be in a position to respond to specific questions on policy and decision making no

matter how well briefed. Authorities should consider requesting additional representation in these circumstances. The Tribunal would be likely to look favourably on these requests.

Hereford and Worcestershire were successful in defending their decisions not to support home-based programmes. This was felt to be because the cases have been:

- prepared thoroughly from every angle, and the Specialist Senior Educational Psychologist was given 8 days to research the topic. This resulted in a paper, which provided a useful comprehensive response to the research data submitted by parents.

Expertise:

- A legal industry has developed around home-based programmes, leading to some solicitors/barristers specialising in the area. It should therefore be assumed that these professionals have acquired an in-depth knowledge and level of 'expertise', which leads to recommendations through lobby groups to parents. Legal representatives in their support of specific therapies can often be critical of others e.g. TEACCH. It therefore follows, that in their response, LEAs will need to be passionately defensive of their provision. PEACH provide parents with a 'pack' of information giving precise instructions on how to prepare and present funding requests to LEAs and SEN Tribunals. LEAs should be aware of the 'pack' contents.
- Detailed critiques of research findings should be included in LEA's submissions. An expert witness (probably an EP) will need to have a thorough understanding of testing & evaluation.
At a tribunal attended by one of the participants of the group, it was noted that one such legal representative might have misinterpreted data from Division TEACCH (e.g. Schopler, March 1998).
- There is an abundance of useful professional papers often written by LEA employed Educational Psychologists, details of which are readily accessible through the partnership.

Evidence:

- Parents are likely to make large detailed submissions. Match it, and address every point raised.
- The tribunal has a legal duty to consider the efficient and effective use of resources. Assume that the tribunal will consider the appropriateness of what the LEA is offering before considering the merits or otherwise of a home-based programme, if it is demonstrated to (a) meet the child's needs and (b) be significantly cheaper than the home-based programme.
- Question the costs of the home-based programme and raise the issues of equal opportunities and employment of therapists, including police checks and health and safety. Counsel has advised us, that LEAs cannot at this moment in time, legally fund programmes by passing payment directly to parents.
- Demonstrate the quality of the LEA provision, ideally within the written submission. Use examples of progress made by other pupils within the authority.
- You will need to demonstrate progress if a child has been educated in a maintained provision.

Presentation:

You can submit video evidence, if it supports your case. If you do this, you must send 5 copies of the tape to the Tribunal with your written submission.

Be prepared for an impassioned speech, and give a sensitive, firm and objective response.

Formally ask for details of the therapists, trainer and supervisor's qualifications.

General Point:

LEAs should not underestimate the planning time that needs to be given to preparing the written submission, witnesses and presentation.

Appendix hb5

Guidelines for Educational Psychologists:

A process for reviews (monitoring and evaluation).

Assumptions:

- ◆ Pupils have already started Lovaas (well) before EP's first annual review
- ◆ Targets are being set through negotiations between parents and Lovaas consultant
- ◆ Parents will have some inclusion in mind (not always in mainstream), but they may have no LEA professional making the link for them
- ◆ There will be a complex history, with emotional investment of parents in 'finding a solution' or 'cure'.

The Educational Psychologist should not aim to:

- ◆ Evaluate the Lovaas teaching approach
- ◆ Monitor and evaluate goals and targets set by the Lovaas consultant (other than descriptively – using performance on Lovaas programmes to help describe current levels of functioning)
- ◆ Assess and monitor the child's progress in isolation from longer term targets and aims
- ◆ Hypothesise the child's possible levels of social interaction with peers, from observation in the home or even from reports from parents and tutors

Ingredients of a meaningful role would include:

- ◆ Making time to listen to parents non-judgementally and build a bridge for joint planning and negotiation
- ◆ Obtaining a general baseline across all development and skill areas (using observation, broad charts, enquiry etc. See section on Monitoring and Evaluating home-based programmes.)
- ◆ Helping parents understand the balance of teaching approaches needed to help a child with an ASD progress both socially and academically
- ◆ Negotiating realistic and meaningful goals for the child in terms of inclusion (through contact with a local school as well, if this link is already in place)
- ◆ Setting targets which all agree will help the child towards the goals – confirm current skill levels in relation to targets. Increasingly these should also be

discussed and negotiated with the link school

- ◆ Relating targets to strategies and current Lovaas programmes so that alternative means can be used, if necessary, to work towards them (or at least, gaining agreement from Lovaas supervisor and tutors that they will use targets to help choose relevant ABA programmes).

Future reviews would assess progress towards targets, redefine targets as necessary and continue the process of active listening and negotiation of goals.

*The EP acts both as a **psychologist and representative of the LEA** throughout.*

Normative testing should only be carried out to evaluate progress in specific areas in order to gauge generally where the child is up to in terms of likely inclusion in school. There should also be an opportunity to advise parents on aspects of management within the home community and to work with the link school towards taking increasing responsibility for the child – ensuring that the aims embrace an attitude of ‘this child belongs here’.

Issues that relate to **working towards meaningful inclusion** include:

- ◆ Moving towards the time when the child will be on the role of local school
- ◆ Placing the child in age-appropriate class
- ◆ Transferring LSA time to school’s budget (so they are not ‘outsiders’ and are accountable to school)
- ◆ All parties aiming for success (allowing for honesty if difficulties occur or inclusion fails)
- ◆ Support for the school to write an IEP which is accepted by parents and Lovaas workers – with home programmes devised to support this
- ◆ Discouraging Lovaas consultants (whatever their nationality) from advising on inclusion – this should be left to LEA and parents to pursue.

In essence, the transfer is from a child centred, target-setting process (Lovaas) to a pragmatic goal-setting approach, based on inclusion, which can reflect back on ABA programmes.

Source: David Bate, Specialist Senior Educational Psychologist, Staffordshire

Appendix hb6

Early Bird Costings

Staffing

For 3 programmes / one year / 20 families

1 x Teacher – 0.6 - 0.7 fte

1 x NNEB / Assistant Psychologist/ Speech and Language Therapist - full- time

1 x Psychologist - Management responsibility, 0.5 days every 2 - 3 weeks, plus efficacy study (NB Efficacy study is not now necessary for participation in programme) (£4 – 6,000)

Clerical support - £3 – 4,000 per annum

Travel

£1,500 -£2,000 (based on 70 miles per day)

Maximum caseload for team

20 children

Sundries

Stationery, photocopying, postage + parents' handbooks -£15 per copy

There may also be some set-up costs if the necessary AV equipment and toys are not available, e.g. – video recorder, 2 portable TV/videos, 2 video camcorders, blank tapes. Leicestershire received a grant of £2,000 capital expenditure for setting up a new venture.

Training costs

It takes a team of (at least) 2 professionals to run the programme. From January 2001, the cost of the 3 day Early Bird training course for the professional team will be £675 + VAT, together with £100 for the course materials, per person.

Total budget (index-linked) £45,000 per year for 20 families

Early feedback from the Early Bird Project and other licensed users around the country regarding running costs suggests that one of the largest expenditure variables is salary costs and these depend on the professionals involved.

Leicestershire ran a pilot project and so employed highly qualified (and therefore more expensive) staff to run the programme. They also ran the optional efficacy study which requires a psychologist. Other programmes around the country, however, have used different professionals, such as an assistant psychologist, instead of a senior psychologist, to run the (optional) efficacy study.

Figures from the Early Bird Centre suggest that on average it costs around £3,000 to run a 3-month programme for 6 families - the biggest variable being the salary costs.

(With thanks to Philip Whitaker, Specialist Senior Educational Psychologist, Leicestershire EPS and Jane Shields, Early Bird Centre Manager)

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Appendix hb7

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