AN EVALUATION OF MULTI-AGENCY SERVICE PROVISION FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

Sophie Nesbitt

Introduction

Autism is a pervasive developmental disorder which affects individuals in varying degrees of severity and is therefore commonly regarded as a spectrum disorder affecting children across the full range of intellectual ability. The majority of individuals with autism will have additional learning disabilities. However, the term Asperger's Syndrome is used to describe people with autism who are of average, or above average intelligence. Autism Spectrum Disorders are characterised by difficulties in three main areas of development, which are known as the triad of impairments:

- Impairment of Social Communication
- Impairment of Social Relationships
- Impairment of Imaginative Thought

Prevalence of autism was estimated at being four or five in every 10,000 (Lotter 1966), however other forms of autistic spectrum disorders such as Asperger's Syndrome show prevalence rates of between 20 and 30 per 10,000 (Wing and Gould 1979).

Autism affects four times more males than females and as many as nine times more males than females are affected in the case of Asperger's Syndrome (Wing 1993). The estimated prevalence rate of autistic spectrum disorders including Asperger's Syndrome is 56 per 10,000 in the UK (Wing 1996).

The increase in estimated prevalence has risen the awareness of autism among parents, professionals and the general public. This increase in awareness can be demonstrated by considerable growth in legislation and guidelines, such as the Children Act (HMSO 1989) and the Code of Practice on the Identification and Assessment of Special Educational Needs (Department of Education 1994) which stresses the need for early identification and assessment, interagency working and the vital role that parents have in the process.

The development of specialist service provision for children and adults with autism in the UK has been pioneered by parent-led organisations. Currently the National Autistic Society runs five schools and a further eight are operated by local

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parent societies (The National Autistic Society 1997a,b). Further specialist provision is made by other voluntary or independent organisations and increasingly, local authorities are developing their own. In some instances the initial project work for these developments are out-sourced to the development and outreach services run by the National Autistic Society, for initial research and development.

This paper outlines findings from a multi-agency research project which aimed to review, evaluate and develop the current levels of service provision for children with Autistic Spectrum Disorders within an outer London Borough. The project was commissioned by the local authority Joint Commissioning Group for Children with Disabilities and conducted by a researcher contracted by the National Autistic Society.

This project had two phases:-

The first stage of this project involved a comprehensive and systematic multi-agency review of the current levels of service provision available to children and young people with Autistic Spectrum Disorders living in the borough. This review resulted in a report making several generic recommendations for service developments to be further researched.

The second stage of the project involved researching proposed service developments in light of recommendations made from the initial stage of the project. This also involved the development of a systematic multi-agency framework for the continued evaluation and development of service provision for the client group.

Method

Professionals

To help identify current levels of service provision available, a semi-structured inter-view was conducted with key professionals within each service. In this meeting the following issues were discussed:-

• Nature and type of service
• Criteria for referral
• Staffing levels
• Levels of experience relating to Autistic Spectrum Disorders
• Number of autistic children currently accessing service

From the above information a structured questionnaire was designed and distributed to other professionals working within these services. The questionnaire aimed to investigate current levels of satisfaction with services. Four areas were investigated:-

• General information - type of work experience, length of work experience
• Knowledge about current levels of service provision
• Methods of collaborative working
• Training needs

Parents

A second questionnaire was designed and distributed to parents. This questionnaire aimed to investigate current levels of satisfaction with services. Four areas were investigated:

• General knowledge about Autistic Spectrum Disorders
• Current levels of service provision received
• Expectations regarding future levels of service provision
• Impact of disorder on family life

All parents who were members of the local Autism Society were surveyed. All parents who had attended the Social Development Team (the local diagnostic service) and gave permission were surveyed.
Results

The following results are divided into two sections:

Section 1: Demographic Information on number of children with Autistic Spectrum Disorders known to service.

Section 2: Outlines general service gaps and proposals for development recommendations obtained from a content analysis conducted on the data obtained from both professionals and parents.

Section 1
(see FIGURE 1, TABLE III, FIGURE 2, TABLE IV, TABLE V, and TABLE VI)

Section 2
General Recommendations

1. Knowledge of available service provisions, such as health, education, social services and the voluntary sector services

Findings from Phase 1

There appeared to be a gap in information relating to service provision available.

The gap in information became visible in two ways:

• many professionals and parents commented on the lack of information available on services and information on how services are accessed and organised.

• many professionals and parents commented on the lack of information available on Autism and Autistic Spectrum Disorders.

Developments from Phase 2

Multi-agency liaison work took place with collation of all information necessary for the development of a multi-agency service directory. This directory will contain detailed information, descriptions and contacts numbers of all services available within the London Borough. The directory will also include specific information on

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TABLE I
Response Rates of Professionals

<table>
<thead>
<tr>
<th>Service Provider</th>
<th>% responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Services</td>
<td>57%</td>
</tr>
<tr>
<td>Health</td>
<td>58%</td>
</tr>
<tr>
<td>Education</td>
<td>87%</td>
</tr>
<tr>
<td>Voluntary</td>
<td>40%</td>
</tr>
<tr>
<td>Mean Response Rate</td>
<td>60.5%</td>
</tr>
</tbody>
</table>

TABLE II
Response Rates of Parents

<table>
<thead>
<tr>
<th>Source of Contact</th>
<th>% responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact with both Local Autism Society and Diagnostic Team</td>
<td>50%</td>
</tr>
<tr>
<td>Contact with Local Autism Society only</td>
<td>31%</td>
</tr>
<tr>
<td>Contact with Diagnostic Team only</td>
<td>19%</td>
</tr>
<tr>
<td>Mean response rate</td>
<td>33%</td>
</tr>
</tbody>
</table>
TABLE III
Demographic Information of Children with Autism within a London Borough

<table>
<thead>
<tr>
<th>Sex</th>
<th>Mean Age (Yrs.)</th>
<th>Age Range (Yrs.)</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>10</td>
<td>4 - 18</td>
<td>4.05</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>2 - 16</td>
<td>4.61</td>
</tr>
</tbody>
</table>

NOTE: a further 8 children are waiting to be seen by professionals
TABLE V
Profile of Education Provision for Children with Autistic Spectrum Disorders in a London Borough

<table>
<thead>
<tr>
<th>Type of Provision</th>
<th>Number of Children with Autistic Spectrum Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre Schoolers</td>
<td>2</td>
</tr>
<tr>
<td>Infant and Junior</td>
<td>28</td>
</tr>
<tr>
<td>Secondary</td>
<td>19</td>
</tr>
<tr>
<td>Out of Borough</td>
<td>4</td>
</tr>
<tr>
<td>Home Educated</td>
<td>1</td>
</tr>
<tr>
<td>Provision Undecided</td>
<td>2</td>
</tr>
<tr>
<td>Further Education</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>59</td>
</tr>
</tbody>
</table>

TABLE VI
Profile of Health Services for Children with Autistic Spectrum Disorders in a London Borough

<table>
<thead>
<tr>
<th>Social Development Clinic (Specialist Diagnostic Clinic)</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ongoing Cases (diagnosed)</td>
<td>42</td>
</tr>
<tr>
<td>Waiting List (guaranteed appointment)</td>
<td>7</td>
</tr>
<tr>
<td>Holding List (appointment not guaranteed until further funding confirmed)</td>
<td>10</td>
</tr>
<tr>
<td>TOTAL</td>
<td>59</td>
</tr>
</tbody>
</table>

both local and national services for children with Autistic Spectrum Disorders. This information includes relevant references and contact numbers, including a detailed description of all current factsheets available from the National Autistic Society.

2. Shared Information

Findings from Phase 1

A major concern throughout the service review was the lack of co-ordinated information available on the number of children with Autistic Spectrum Disorders known to services within the London borough. The information used in the project was gained via the Education Department and the Health Services - Specialist Diagnostic Team. In some instances it was reliant on particular individuals to provide information from memory.

Historically there are 4 different databases of information held within the borough, however presently no children's database is maintained, no classifications that are specific or inclusive of autism apart from Learning Disability are used.

Development from Phase 2

Information on all children with Autistic Spectrum Disorders known to services
was collated. Permission was sought from parents regarding the development of an information database to be held by Social Services. Within Social Services a lead person with responsibility for development and co-ordination of this database was identified. This lead person will take on board the work already done by this project and look toward developing a suitable system for classification of disabilities. This work will be overseen by a multi-agency Steering Group.

3. Training

Findings from Phase 1

Only 21% of professionals working with Autistic Spectrum Disorders had received Autism Specific Training. 40% of professionals commented that Autism Specific Training would be helpful. Within services there appeared to be a gap within specialist training for individuals working with children with Autistic Spectrum Disorders. However, the gap in training was not solely related to Autistic Spectrum Disorders it also appears that there was a lack of training in terms of behaviour management strategies, communication issues and organisation of services. Many of these issues, although not autism specific, are autism related.

Developments from Phase 2

It has been agreed that Training Needs within that London borough will be addressed via a two tier approach:-

The first initiative developed to address some of the training issues identified was an Autism Awareness Afternoon, which was arranged to coincide with the National Autistic Society’s Autism Awareness Week. The afternoon was open to both professionals and parents and was supported with publication literature from the National Autistic Society.

The second initiative was the development of a two day training event to be administered by professionals within the borough. The National Autistic Society agreed to provide additional support when required. The training proposed aimed to cover: organisation of services within the borough, overview of current research and developments, the triad of impairments, strategies for effective practise and autism and challenging behaviour.

4. Family Support Worker

Finding from Phase 1

Many of the findings highlighted the gap in information and specialist knowledge. Parents experienced problems in accessing services and obtaining knowledge about specialist services. Findings suggested that the stress of caring for an autistic child was increased by the inequity and inability to access services quickly.

Developments from Phase 2

The Local Health Authority - Health Improvement Programme - Phase II (Ealing, Hammersmith & Hounslow Health Authority 1998) had recommended the development of an Autistic Spectrum Disorder Co-ordinator Post. It was agreed that the development of this post should take into account recommendations related to the research project. The research project findings should be used as a basis upon which to develop the aims and objective of this post.

It was proposed that the development of this Co-ordinator role should also take into account the findings from an Interagency
Research Project currently being conducted within the local health trust. The task of the project, also jointly commissioned, was to research and develop a link worker system for children with special needs within the borough.

There were several different ways in which this identified service gap could be best filled. It was agreed that different methods be investigated thoroughly before the development of an Autistic Spectrum Disorder Co-ordinator post role goes ahead. This would, hopefully, ensure that services are not replicated in new forms and that the needs of this specialised client group and their carers are fully met in the most appropriate way.

Discussion

As can be seen from the results, much of the service development work initiated by the project was on-going. To ensure that this work was continued once the initial research phase was complete, a comprehensive evaluation system was developed.

The research project has been steered by a multi-agency Steering Group that have met on a six weekly basis. The aims and objectives of this group were to provide support and advice on matters that have arisen from the research.

It was proposed that the Steering Group should continue, however the aims and objectives of this group should be broadened. The Steering Group should have four main objectives:

Objective One

The main agenda of the group should be the continued strategic development of outstanding project recommendations. Progress could be monitored by the development of an action plan, the basis for this could be taken from the main findings of the project. This development plan could then be fed back via the Joint Commissioning Group at regular intervals.

Objective Two

The Steering Group should aim to expand it's membership and include professionals and parents from adult services, in this way it could work towards raising awareness of the client group among the adult services from an earlier point, allowing adult services to plan for service developments. The group could also aim to tackle related issues such as transition - which have been difficult to tackle within the current project as it's task was restricted to children services.

Objective Three

The Steering Group should aim to develop some form of Special Interest Group, which aims to raise the general awareness of Autism at different levels. This could include inviting outside speakers to talk about current developments within the field. Within this, the group could also fulfil some training criteria.

Objective Four

If the Health Authority Improvement Programme Recommendation is commissioned, the group should aim to have some type of supervisory input into the development of the post of Autistic Spectrum Disorder Co-ordinator.

From the results it was proposed that the research report could be used as a basis on which to develop an “Agenda for Action”
for the Steering Group. At the initial stages of development this was to be kept deliberately brief, the idea being that for the action points to be meaningful to the group they needed to be developed on a consensus basis with the focus on group consultation and discussion.

**Summary**

A multi-agency service review was conducted aiming to evaluate and develop current levels of service provision for children with Autistic Spectrum Disorders within an outer London Borough. The project was commissioned by the local authority Joint Commissioning Group for Children with Disabilities and conducted by a researcher contracted by the National Autistic Society from July 1998 to May 1999.

The review used both qualitative and quantitative research methods, taking into account the views of both parents and professionals within the borough. From the findings several service gaps were identified and recommendations made for service developments.

This paper outlines the review process and subsequent developments made, highlighting the value of working within a framework which incorporates both professional and parental views. The project work undertaken also acknowledges the importance of developing an on-going evaluation model to enable work that has been initiated to continue. This model of working emphasises the need for services to be developed jointly by health, education, social services and the independent/voluntary sector.

**References**

Ealing, Hammersmith & Hounslow Health Authority (1998). Health Improvement Programme - Phase II. Children's Services


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