

A Study of Parental Perception

of

Services offered by a Multidisciplinary Communication Clinic

for

Children with Autism Spectrum Disorders

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ABBREVIATIONS

| | |
|--------------|--|
| ASD | Autism Spectrum Disorder |
| AS | Asperger Syndrome |
| NIASA | National Initiative for Autism Screening and Assessment |
| ECM | Every Child Matters |
| NSF | National Service Framework |
| MMR | Mumps Measles and Rubella vaccine |
| MRC | Medical Research Council |
| ADHD | Attention Deficit Hyperactivity Disorder |
| CAMHS | Children and Adolescent Mental Health Services |
| GP | General Practitioner |
| SALT | Speech and Language Therapy |
| NHS | National Health Service |
| NAS | National Autistic Society |
| OCD | Obsessive Compulsive Disorder |
| Q | Question |

ABSTRACT

Objectives

To explore parental views of the diagnostic services offered by the Communication Clinic for children with Autism Spectrum Disorders in Lewisham

To use this information to identify areas for improvement in provision of diagnostic services for children with Autistic Spectrum Disorders

Design

A descriptive study based on postal questionnaires

Participants

Parents and Carers of children in whom a diagnosis of Autistic Spectrum Disorder was made between January and December 2004

Results

Of the 79 parents to whom the questionnaires was sent only 24(30%) responded. Of the twenty four parents twenty two (92%) felt satisfied with the overall services. Twenty three out of twenty four (96%) parents felt that the diagnosis was explained well. Twenty out of twenty four (84%) felt that the assessment was helpful. Twenty one out of twenty four (92%) parents felt that the waiting time was too long. Fourteen out of twenty four (60%) stated that they did not receive any support after diagnosis.

Conclusions

Majority of parents were satisfied with the diagnostic services despite over three quarters stating that the waiting time was too long. Over half of the parents felt that they received no support after diagnosis.

Although the response rate was low the parental views and comments highlighted the areas that need improving. Parents felt strongly about the delay in diagnosis due to long waiting time and lack of access to support after diagnosis. The long waiting time for assessment has been acknowledged by the services and various measures have been put in place to try and reduce the waiting time. The number of children diagnosed per year has risen and this has placed increasing demands on the after diagnosis support service. The results suggest that there is an urgent need to reduce the delay in diagnosis and provide comprehensive after diagnosis support to families of children with ASD.

LITERATURE SEARCH

A literature search was undertaken.

Databases searched are

COCHRANE

MEDLINE

EMBASE

CINAHL

National electronic Library for Health

Keywords

Autism, Asperger Syndrome, Autism Spectrum Disorders, Autistic Spectrum Disorders, Autistic Disorders, Atypical Autism, Pervasive Developmental Disorders Not Otherwise Specified, diagnosis, assessment, service delivery, parental questionnaires, family centred services. An advance search was performed; parental views, perception, family attitude to health, patient attitude to health, acceptance of health care, communication, consumer satisfaction, diagnostic services, health care service delivery, service evaluation, multidisciplinary teams, patient, parental survey.

Literature search was undertaken to obtain papers relating to classification, epidemiology, causes, prognosis, screening, diagnosis, assessment and interventions for Autism Spectrum Disorders. A search for papers on evaluation of services, parent and patient surveys, satisfaction with health care, designing questionnaires and papers particularly pertaining to surveys of parents of children with Autism Spectrum Disorders was also undertaken.

INTRODUCTION

Background

Kanner in his 1943 paper on 'Autistic disturbance of affective contact' reported the behaviour patterns of eleven children which he later referred to as 'early infantile Autism'¹. He described 'the children's inability to relate in the ordinary way to people and to situations from the beginning of life'². In 1944 Hans Asperger in Austria described a different but related behaviour pattern called 'autistic psychopathy' now referred as Asperger Syndrome³.

Rutter proposed a diagnostic criteria for childhood autism in the late seventies⁴. Lorna Wing described the triad of social, communication and imagination impairment, and used the umbrella term Autism Spectrum Disorder or Autistic continuum to describe the group of autistic disorders⁵.

Autism Spectrum Disorders are now recognized as a group of neuro developmental disorders characterized by early emerging qualitative impairments in social interaction, social communication and imagination with a restricted range of interests and stereotyped repetitive behaviours and mannerisms.

Classification

The diagnostic criteria for autism are set out in the ICD-10 (International Classification of Diseases, 10th revision)⁶ and the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders)⁷.

‘Many clinicians find that although Autism Spectrum Disorder does not appear in the DSM-IV or ICD-10 criteria, it is much more easily understood by parents and professionals than Pervasive Developmental Disorder’⁸. The term ASD provides a clearer representation of the continuity between Autism and related disorders within the spectrum⁹. The two terms Pervasive developmental Disorder and ASD are now used synonymously.

The criteria for autism (autistic disorder, childhood autism, autistic syndromes) currently agreed by most authorities are;

1. severe abnormality of reciprocal social relatedness
2. severe abnormality of communication development including language
3. restricted repetitive behaviour, interest, activities and imagination
4. early onset (before 3 to 5 years).¹⁰

Gillberg also used a broader label of Autism Spectrum Disorder which includes Autism, Asperger Syndrome, Atypical Autism or Pervasive Developmental Disorder and Childhood Disintegrative Disorder¹¹.

Asperger Syndrome

The diagnosis of Asperger syndrome is made in children who meet the criteria with normal early language development.

Pervasive Developmental Disorder Not Otherwise Specified/ Atypical Autism

This diagnosis is given to children with all three symptoms in atypical form or with two of the symptoms in typical form. The ICD-10 criteria of Atypical Autism would equate with DSM-IV criteria for Pervasive Developmental Disorder Not Otherwise Specified.

Childhood Disintegrative Disorder

Developmental regression at the age of 3-4 years characterized by restlessness and hyperactivity before the child develops autistic pattern of behaviours.

Prevalence and Incidence

It has been widely accepted that the prevalence of ASD has increased over the recent years. There is increasing consensus that the prevalence of Autism Spectrum Disorder is 60/10,000^{12 13}. Chakrabarti and Fombonne reported a rate of 62.6 per 10,000 in preschool children¹⁴. Wing et al proposed possible reasons for increase in the prevalence; change in

the criteria for diagnosis, differences in the methods used in studies, increasing awareness among professionals and parents, greater willingness by educationalists and the parents to accept the diagnostic label, recognition that ASD can be associated with other medical, developmental and learning difficulties and the development of specialist services¹⁵. It has also been shown that the age at diagnosis has decreased over time.

It would be difficult to calculate the incidence rate of ASD because the age of onset is very difficult to ascertain. Moreover the studies reporting incidences have relied on records and used the year of diagnosis as the year of onset^{16 17 18}.

It was hypothesised by Wakefield and colleagues that the observed rise in rates of ASD was due to a new variant regressive autism related to MMR vaccine^{19 20}. The incidence studies noted a steady rise year by year but this increase was unaffected by the introduction of MMR^{16 17 18}. Fombonne et al examined epidemiological data and found no evidence to support a distinct syndrome of MMR induced autism²¹. The claims that MMR vaccine is associated in the initiation of autism are not supported by any credible scientific evidence, while there is more compelling evidence showing no association²². In a recent study it was reported that prevalence was stable when comparing two cohorts of children over a ten year period¹⁴.

Gender

The prevalence of autism in boys is considerably higher than in girls and the ratio is reported to be 3.5 or 4.0 to 1^{23 24}. The cause for the observed sex difference remains the topic of debate. It is possible that males have a lower threshold for expressing the disorder and that more severe neuro-developmental abnormality are required to cause autism in a girl²⁵.

Causes

Genetic basis

It is now clear that ASDs have a genetic basis. Studies have shown that the concordance rate for autism is much higher in monozygotic than dizygotic twins^{24 26 27 28 29} implying that ASD is a highly heritable disorder which involves complex mechanisms with interaction of many genes. Single gene disorders and chromosomal disorders affect a small proportion although majority of ASDs result from complex genetic influences. The International Molecular Genetic Study of Autism Consortium conducted a two staged genome search for susceptibility loci in autism; regions on 6 chromosomes were identified (4, 7, 10, 16, 19 and 22). The region on chromosome 7q was found to be the most significant³⁰.

The recurrence risk to siblings of children with ASD is around 3-6%, about fifty to hundred times higher than the risk in the general population³¹. The sibling risk is higher, about 20% for the broader phenotype³¹. There is increased language and learning difficulties and psychiatric illnesses in the first and second degree relatives.

Environmental

The MRC review of autism research, looking at the possible environmental factors concluded that there is insufficient evidence to confirm any association³². The only environmental factors possibly associated with autism include thalidomide use, certain viral infections in-utero and maternal anticonvulsants, yet these account for only a tiny fraction of cases³³.

Co morbidity

Co morbidity in ASD is common³⁴. Significant learning difficulties occur in about 80% of classical cases of autism²³. Other disorders such as tuberous sclerosis, metabolic and chromosomal disorders are present in 10-25% of cases¹⁴. In addition epilepsy, hearing and visual impairments are very common. Neuropsychiatric problems such as ADHD, Tourette syndrome, tic disorders and depression also co-exist with ASD.

Identification and Assessment

Lorna Wing recommended that 'identification of ASD requires expertise, experience and time. If the procedure is rushed and the right questions not asked, the diagnosis can be missed'⁹.

‘Although screening might enable earlier diagnosis allowing time for earlier interventions, parental support, and genetic counselling, there is currently insufficient evidence to recommend screening for ASD’³⁵. Child health promotion gives the primary care staff the opportunity to discuss the individual child’s development and provides parents with a forum to raise any concerns so that referrals can be made promptly for further assessments if appropriate³⁶.

It is increasingly recognized that parents are better at recognizing developmental delay in their children as shown by Glascoe et al when using PEDS – Parent Evaluation of Developmental Status³⁷. Diagnosis can be difficult in younger more able children and children with significant learning difficulties and other co morbid psychiatric conditions. Screening for developmental problems by professionals has low sensitivity and specificity. Screening tools such as CHAT Checklist for Autism in Toddlers³⁸ has high specificity but low sensitivity. This screening tool missed high and low functioning children³⁹. However it was found to differentiate children with Autism and developmental delay⁴⁰.

In early years education and in schools the educational staff are becoming aware and have developed expertise in recognizing the alerting signals in children. Screening tools such as Social Communication Questionnaire and Childhood Asperger Syndrome Test CAST⁴¹ can be used to identify the need for assessment.

It has been shown that clinical diagnosis can be made as early as 2 years⁴². Howlin and Moore found that although parents were concerned about the child's development as early as 18 months the formal diagnosis of ASD can be delayed⁴³. It has been shown that the mean age of diagnosis of autism is 5.5 years and as late as 11 years for AS, in spite of earlier parental worries⁴⁴. However despite increasing awareness, a number of barriers to early diagnosis still exist such as failure to recognize symptoms, denial of problems by parents and professionals, failure to get referral, waiting for appointment, inadequately trained staff and separate waiting lists for different professionals³⁵.

Gould stated that the primary aim of clinical assessment is to 'examine the profile of the skills and impairments of the child in order to identify their special needs .Parents are partners with the professionals in this process'.

Assessments are carried out in a multidisciplinary setting with Community Paediatricians, Speech and Language Therapists and Clinical Psychologists. Some units also have multi-agency involvement with specialist teachers and family support workers contributing to the assessments. The main aim of the assessment is to address parents' concerns and outline child's strengths, difficulties and needs. The assessment should include detailed coordinating information from relevant professionals and agencies. It also involves detailed and specific developmental history, description of child's level of

functioning, family history and accounts of behaviour using a semi structured interview. Various diagnostic tools have been used for assessment, including CARS (Childhood Autistic Rating Scale), ADI (Autism Diagnostic Interview –revised)⁴⁵, ADOS (Autism Diagnostic Observation Schedule – Generic)⁴⁶, DISCO (Diagnostic Interview for Social and Communication Disorders)⁴⁷, and locally designed proformae using ICD-10 criteria.

Assessments of communication by specialist Speech and Language therapist, focused observations across different settings and baseline cognitive assessment by the psychologist contribute towards the diagnostic process and identifying the children's needs. Physical examination to identify any co existent conditions needs to be part of the assessment. Investigations are not routinely recommended as the pick up rate for abnormal chromosomes and other metabolic and neurological investigations is quite low.

Assessment has to be an ongoing process; it not only involves diagnosis but identification of the changing needs of the children and their families during the course of childhood. This is particularly important in children with co morbid disorders which require additional specialist support. There is an increasing need for ongoing support for these children and families as their behaviour and mental health needs escalate during adolescence and early adulthood. Hence access to CAMHS is vital.

Interventions

It is acknowledged that early interventions that assist children and families to develop appropriate management strategies to increase social communication skills for the child and the family may prevent development of secondary behavioural problems⁴⁸. General principles of needs led, child and family focused interventional measures should be considered. A named professional acting as a key worker is invaluable in supporting the families especially following the diagnosis. The National Service Framework recommends a holistic, multi-agency, well coordinated approach to providing services for children with special needs⁴⁹.

Families of children with ASD take on different roles⁵⁰. Specific interventions include parent training courses such as Early Bird and 'help!'⁵¹. A number of different models of interventional programmes have been proposed and used worldwide. Educational programmes that are successful employ a structured approach to teaching, focusing on the development of specific skills and increasing social communication and understanding⁵². Management of co morbidities such as epilepsy, ADHD, anxiety, OCD, depression warrant pharmacological interventions. Medications are also used as part of coordinated approach to behaviour disturbance.

Prognosis

Howlin noted that the outcome in school work and social functioning is varied⁵³. Of individuals suffering from autism, 75% had a poorer outcome and 25% a better outcome. Acquisition of language before age of 6 years, IQ levels above 50 and having a special skill predict a good outcome⁵⁴.

It was found that with respect to independent living and employment there was not much difference between high functioning individuals with autism and those with autism. For people with severe autism, independent living and social functioning are unlikely; for those with higher functioning autism the jobs acquired are often below their educational level.

Service Provision

Recent department of health documents on services for children and young people have placed increasing emphasis on child and family centred and needs led approach with parental involvement at every stage⁴⁹. Supporting parents and carers is at the heart of the government green paper ECM's approach in improving children's lives⁵⁵. It recommends that timely and early identification, assessment and interventions should be provided for children with ASD⁵⁶. It also reiterates that professionals should strive to "canvass the

views of the children and families and to openly discuss good and not so good aspects of services⁵⁶. The NSF the 'Emerging findings'⁵⁷ document suggested development of user forums to enable user's views to be incorporated in improving services. It is also important to work closely with parents and involve them in the decision making and planning process. It is widely acknowledged that parent involvement is vital in the strategic and operational levels to best deliver a child and family focused services³⁵.

Population Characteristics in Lewisham

Lewisham has a population of 249,000⁵⁸. It has around 63,000 children and young people under the age of 19 years⁵⁹. It is an ethnically and culturally diverse reasonably deprived borough of London. Twenty percent of Lewisham's population is aged 15 years and under. Almost half of Lewisham's children aged 0-19 years are from Black and Ethnic minority group. A substantial proportion of children live in poor circumstances. Twenty six percent of households with children under 16 have no working parent. Thirty four percent of households are headed by a lone parent⁵⁹. Lewisham ranks 57th most deprived borough in the country and 13th of the London boroughs⁵⁹. It is estimated that there are 1400 disabled children in Lewisham, a fifth of who are under 5 years. At the end of 2004 there were about 500 children under 19 years with ASD in Lewisham.

Lewisham Communication Clinic Service

The Communication Clinic offers multidisciplinary diagnostic assessment, recommendations on management, liaison with other agencies and support for children with ASD and their families. Members of the team include Community Paediatricians, Child Psychiatrist, specialist Speech and Language Therapists and Clinical Psychologists. The Lewisham Autism Support set up in 2003 gives early support to families of newly diagnosed children and some limited crisis intervention. This is mainly an information and signposting service and currently does not give ongoing support to families.

There are clear referral pathways to the Clinic.

Referral Pathway

Under 5 Years

Over 5 Years:

Parental/Professional

Concerns



Health Visitor/GP/Early Years Education

Education/ GP/CAMHS



Referral to Child Developmental Service



Developmental Assessment

SALT Assessment

School Medical Assessment



Referral Meeting/Information Gathering



Communication Clinic Waiting List

The Communication Clinic has attracted ever increasing referrals, as ASD awareness has increased amongst professionals in health and education and among parents. There is good primary care recognition of Lewisham children especially by health visiting staff and GPs. There are many school aged children often with more subtle difficulties who are referred for assessment for the first time. In the past these children would have been missed or have their needs categorized differently. Many children who have been under the care of CAMHS are now being recognized to have ASD. Another expanding group referred includes children where ASD is recognized in addition to an existing diagnosis for e.g. Cerebral Palsy, Down syndrome, Learning Difficulties and Severe Visual Impairment.

Referrals have increased steeply over the past 6 years. This has resulted in long waiting time with children waiting for over 12 months for an assessment. Early and prompt assessment and diagnosis is the primary aim of the clinic. However increasing demands in terms of rising referrals and not enough trained staff had led to the inability to maintain service standards of access to assessment within 3 months. The waiting times had increased from 10 months to over a year in 2004. A number of steps had been initiated to reduce the waiting time for assessment.

On receiving a referral the parents and the referrers are sent acknowledgement of the referral. An appointment is then sent with an information leaflet on the Communication

Clinic. The assessments involve detailed history taking using a semi structured interview, review of previous developmental and speech therapy reports, observation of the child's communication, social interaction and play and medical examination of the child. This is done over a 2 hour period. The members of the team meet and discuss the results of the assessment and agree on the diagnosis. The results are fed back to parents on the same day. The child may have been visited at home or the nursery by one of the members of the team before the clinic if appropriate.

The diagnosis is explained at length and implications for the child and family are discussed. The child's strengths, difficulties and needs are outlined. Investigations and referrals to other relevant agencies are made as appropriate. Time is allowed for parents to ask questions. The parents are given the name and contact information for a member of the team. The parents are given information on parent training course, local parent group, and benefits. The NAS information pack. is also given to parents. A detailed report of the assessment is first sent to parents and their permission sought before dissemination to relevant agencies and professionals. A review appointment is made to further discuss issues and answer parents' queries. Ongoing follow up is offered by the patch Community Paediatrician.

Evaluation of services

“Efforts to improve health care will be wasted unless they reflect what patients want from the service”⁶⁰.

Evaluations are patients’ reactions to their experience of health care⁶¹. Evaluation of services ascertains whether the process or outcome of their care was good or bad. Patient experience is stated as one of the three areas for measuring quality of care⁶². Evaluation has become a central aspect of service provision in the NHS and it has been recognized that there is need to appraise services and their clinical outcome.

Patient involvement can also result in better processes and outcome of care. It makes clinicians more responsive to patients preferences, contributes to better implementation of clinical guidelines, engages patients in redesigning processes and results in better satisfaction with care⁶³. Patient satisfaction is an important measure of quality of care. Surveys of patient satisfaction should be integrated into continuous process of providing and improving care⁶³.

It is increasingly acknowledged that service providers need to identify users service values and what issues they find important rather than make assumptions based on professionals' belief. Feedback from service users should be incorporated in service delivery and used to implement changes in the service.

There are different dimensions of patient satisfaction; information, overall quality, access to services and competence⁶³. The two characteristics of service delivery that influence parents perception are the process and the structure of service delivery⁶⁴. The process centres on the way in which the services are delivered including components such as interpersonal relationships providing respectful care and service continuity. The structure that influence perception of care and satisfaction consists of factors such as physical comfort, waiting lists and ease of access to services⁶⁵.

There are various methods of evaluating services and it depends on the services being provided, choice of the population, the timing of the survey, type of questions being used, method of rating the satisfaction, reliability and analysis of the finding. The evaluation tools can take the form of questionnaires to assess patients' needs before a consultation, focus groups with patients and surveys among patients to provide feedback to service providers, interviews or outcome measures.

“Questionnaires that ask for evaluation of health care in terms of satisfaction or dissatisfaction show less discrimination than questionnaires that use terms such as good or bad, agree or disagree with concrete aspects of care⁶⁶. Qualitative in depth interviews with parents and focus groups help validate response gained from questionnaires⁶⁷. It is important to collect demographic data of parents as shown by the Picker institute of Europe in their satisfaction questionnaire⁶⁸. Although it is important to consider views of the users in the development of services, the validity, effectiveness and implementation of these methods need to be examined carefully. Patients reports of their care can be compared with the medical notes or clinician reports of the care delivered⁶⁹.”

Questionnaires could be postal self completed, or administered during a face to face interview or completed electronically. The advantages of the self completed questionnaires are preservation of anonymity, low cost, less time needed to administer, less need for trained staff, and the opportunity to include larger more geographically spread population. The biggest disadvantage is the poor response due to various reasons. Non responders are more likely to be ill, less satisfied with care and less frequent users of health care than responders^{70 71}. It is important to guard against biases such as non response and reporting (information) bias.

It is paramount to engage parents in the process of planning, implementing and delivery of services. Their views are invaluable in developing a child and family centred service.

This research will attempt to look at parental views on the diagnostic services offered by the multidisciplinary Communication Clinic, in Lewisham in order to identify areas for improvement and to guide future planning of services.

THE STUDY

Aim of the Study

Following the institution of various measures to optimise the standards of the diagnostic services it was imperative to explore parental perception of the diagnostic services for children with Autistic Spectrum Disorders.

To explore parental perception of the diagnostic services offered by the Communication Clinic for children with Autistic Spectrum Disorders in Lewisham.

To use this information to guide future planning and provision of services for Children with Autistic Spectrum Disorders

Design

This is a descriptive study of parents' views on services offered by the multidisciplinary Communication Clinic for children with Autistic Spectrum Disorders in Lewisham based on postal questionnaires.

METHODS

Inclusion criteria

Parents and carers of children in whom a diagnosis of Autism, Autism spectrum Disorder, Asperger Syndrome, Atypical Autism /Pervasive Development Disorder Not Otherwise Specified was made

Exclusion criteria

Parents and carers of children with one of the above diagnosis and for who addresses were unavailable

Parents and carers of children who were not diagnosed to be on the autistic spectrum

Study Period

The study period was from 01.01.2004 to 31.12.2004. This period in 2004 was chosen because changes were introduced in 2003 to reduce waiting list by increasing the number of clinics and training doctors and speech and language therapist to contribute towards assessment. It was important to evaluate parental perception in view of the recent changes.

Data Collection

The list of children seen in the Communication Clinic during the period between 01.01.2004 to 31.12.2004 was obtained from the Communication Clinic database. This list was cross checked with the database of children seen in the Clinic maintained by the specialist speech and language therapist. The diagnosis was confirmed by looking at the clinic reports of all the children seen in the clinic during the study period.

One hundred and eleven children were seen in the Communication Clinic, of whom 82 children were diagnosed as being on the spectrum during the study period. One of the children was looked after by the local authority and due to legal reasons the address was not divulged, and he was excluded from the study. Two families had moved out. Hence these three children were excluded. The parents of 79 out of 82 of these children were invited to take part in the questionnaire survey in writing.

Data was also collected from the case records in order to compare the responders and non responders. Age when seen in clinic (age at diagnosis), sex, diagnosis, co morbidities, family status and post codes of residence were collected from the case notes of all the 79 children. Attempts at collecting data on ethnicity, parents' age and occupation proved to be futile as this information were not consistently recorded in the notes. Less than 20% of the notes had these data available.

Extensive discussions about the study were undertaken with the members of the multidisciplinary team, the local parent group and the Lewisham Autism Planning Group.

Initial plan to conduct telephone interviews of a random sample of parents to validate the answers given in the questionnaires were not conducted because of time constraints.

Questionnaire design

An anonymised postal questionnaire(Appendix 2) was designed⁷² to evaluate parental perception of services together with information sheet (Appendix 3) and consent form Appendix 6). A series of closed and open ended questions were used. The questionnaire was divided into four sections; pre assessment, assessment, after assessment and a section on summary, looking at good and not so good aspects of the assessments and parents' suggestions. The questions covered the structure and processes of service delivery that need to be addressed when evaluating services⁷³.

The pre assessment part of the questionnaire focused on the information and support offered prior to the assessment. The next part was designed to gather information on parental views on the actual assessment including the child and family centred approach in listening to the parents concerns, discussing the child's abilities and needs, explanation of the diagnosis and the parents' feelings on receiving the diagnosis. The after assessment

part focused on the quality of the detailed report (the assessment report explains the child's diagnosis, and the processes which informed their decision, child's strengths, difficulties, needs, a clear plan and a follow up plan) and the support following the diagnosis. To summarise, parents were asked to comment on the good and not so good aspect of the diagnostic services and were asked for suggestions to improve services.

Questions on premises and access were deliberately avoided because a purpose built Children's Centre is being built in Lewisham and there has been an extensive consultation with the service users in planning of the new centre. Parents and the multi disciplinary team were consulted when designing the questionnaire. The Questionnaire was piloted amongst a small group of parents who gave invaluable feedback. Appropriate changes were made to the questionnaire before administering it to the study sample. The 79 eligible parents /carers were invited to participate in the study in writing (Appendix 1).

Various measures were taken to increase the response to the survey.

The results of the systematic review on questionnaire design and survey was considered while designing the questionnaire⁷⁴. The names of the parents and the carers were used to personalise the letters and stamped return envelopes were used. To ensure names and addresses were up to date details were cross checked with GP records. Each questionnaire was numbered and the corresponding list of names was kept separate from the questionnaires. A reminder letter (Appendix 4) and a second copy of the questionnaire

was sent two weeks later. Each child's GP was informed of the study in writing (Appendix 5).

The data from the postal questionnaire were entered into Microsoft Excel database and cross tabulations and frequencies were performed. The notes of all seventy nine children were examined to gather demographic data to compare responders and non responders. Information collected from the notes regarding follow up appointments and parents receiving copy of the report was used to validate the answers given by the parents.

Ethical approval was applied for and obtained from Lewisham Local Research Ethics Committee. Approval for the study was also obtained from Lewisham Primary Care Trust. Ethical approval was also obtained for telephone interviews to validate the questionnaire but I was unable to conduct this due to limited time.

RESULTS

One hundred and eleven children were seen in the Communication clinic during the study period 01.01.2004 to 31.12.2004. The clinic reports of all the 111 children were examined to ascertain the diagnosis. Twenty eight children were identified as not being on the Autistic Spectrum. Eighty two children were diagnosed as having one of the following, Autism (n=29), Autistic Spectrum Disorder (n=39), Asperger Syndrome (n=6) Atypical Autism (n=3), PPD NOS (n=2). Two children had moved out of the area and no forwarding addresses were available for these children. The questionnaire was not sent to one of the children for legal reasons. The questionnaire was sent to parents/cares of 79 children. The median age of the children was 6.3 years and only 3 were girls. Only twenty four questionnaires were returned. All the 24 returned Questionnaires were eligible for analysis.

Of the 79 parents to whom the questionnaires were sent only 24(30%) responded. Of the twenty four parents, twenty two (92%) felt satisfied with the overall services. Twenty three out of twenty four (96%) parents felt that the diagnosis was explained well. Twenty out of twenty four (84%) felt that the assessment was helpful. Twenty one out of twenty four (92%) parents felt that the waiting time was too long. Fourteen out of twenty four (60%) said they did not receive any support after diagnosis.

Total number of children seen in the Communication Clinic during the study period

(Study Population)

(n = 111)



28 children not diagnosed

Children diagnosed as being on the spectrum

(n = 82)



1 address not available

2 moved out of the area

Number of children included in the study

(Study Sample)

(n = 79)

Total number of Questionnaires posted

(n = 79)



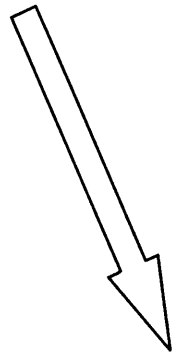
Number of responders

(n = 11)



Number of non responders

(n = 68)



**68 Questionnaires
and reminder letter
sent**

Number of responders after reminder letter

(n = 13)



Total number of responders

(n = 24)

Responders 24 (30%)

Non responders 55 (70%)

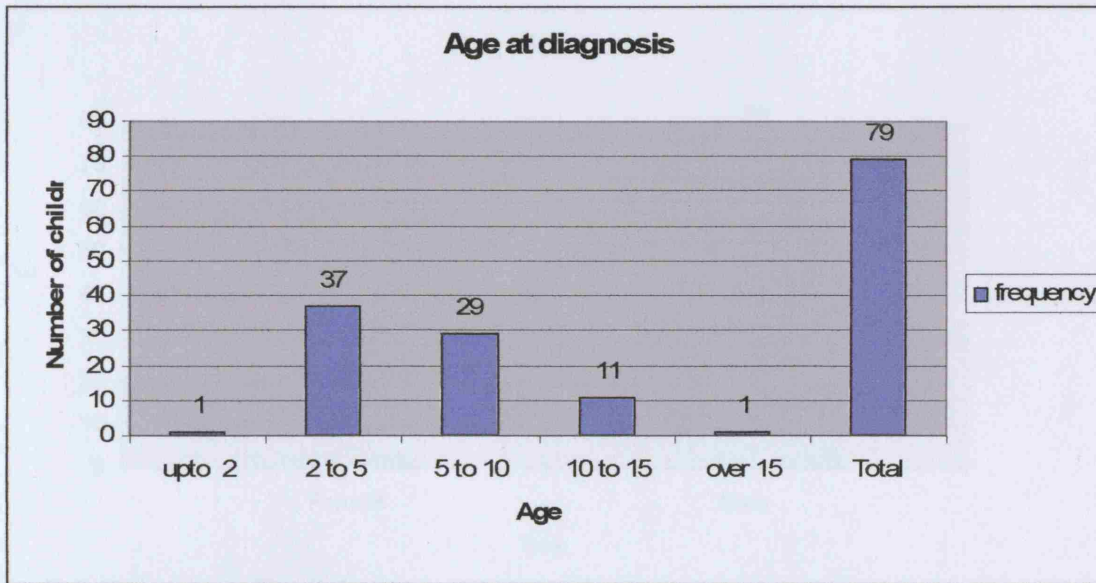


Figure 1: Age at diagnosis

One child was diagnosed at the age of 2 years. Thirty seven (47%) children received their diagnosis between the age of 2 and 5 years. Twenty nine (37%) children were diagnosed between the age of 5 and 10 years. Twelve children (15%) were diagnosed after their 10th birthday.

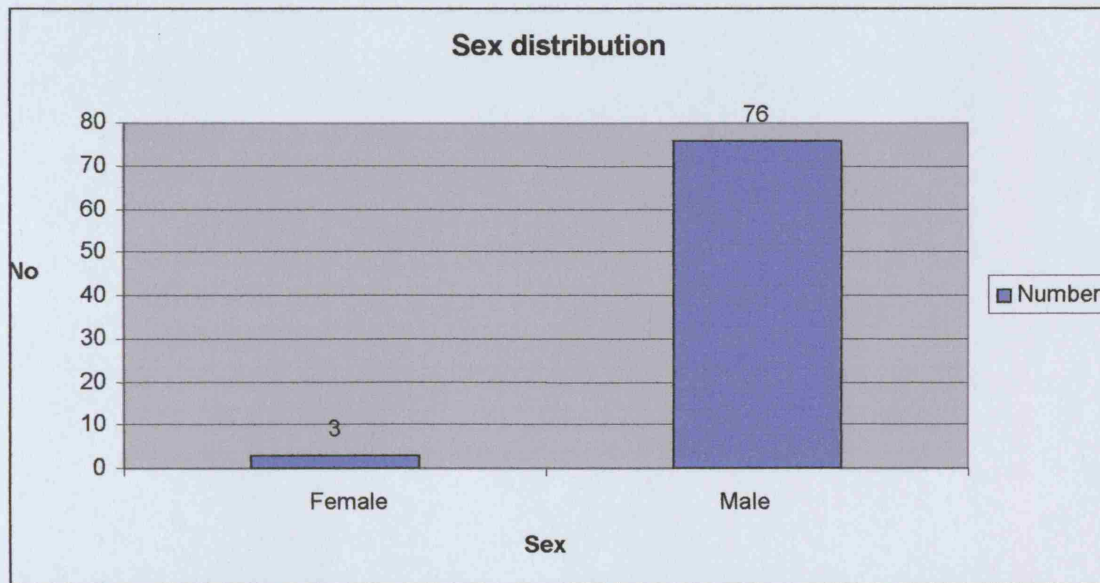


Figure 2: Sex distribution

There were 76 boys and only 3 girls diagnosed during the study period.

Pre assessment

Waiting Time Q1

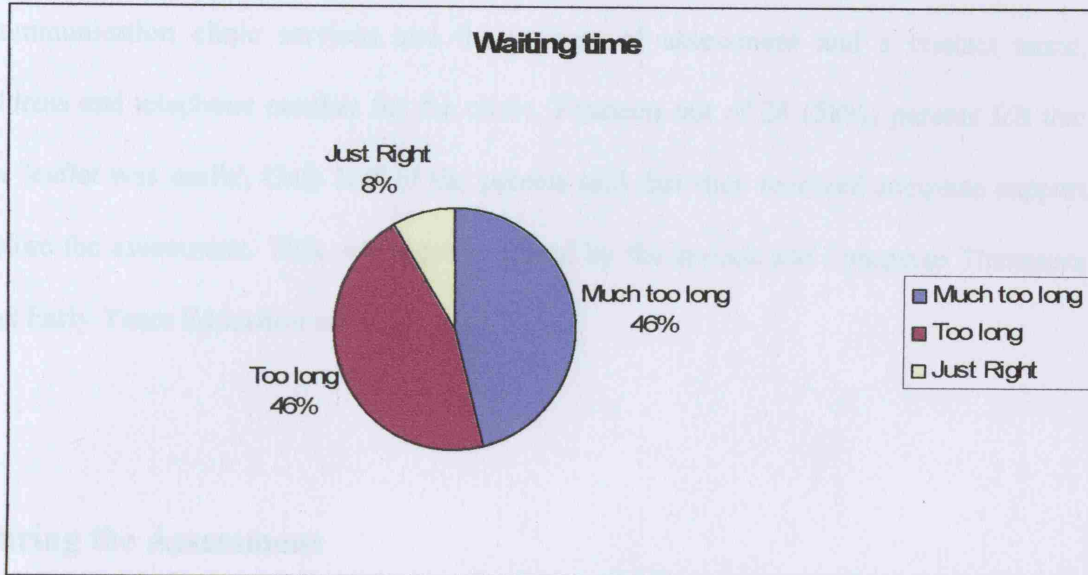


Figure 3: Waiting Time

Of the 24 parents who responded, 22 (92 %) felt that the waiting time was much too long/too long. Only 2(8%) parents felt that the waiting time was just right.

Information and support Q 2

The clinic sends out information leaflets to parents about the Communication Clinic when the child is placed on the waiting list. The leaflet gives information about Communication clinic services and the process of assessment and a contact name, address and telephone number for the clinic. Fourteen out of 24 (58%) parents felt that the leaflet was useful. Only half of the parents said that they received adequate support before the assessment. This was mostly offered by the speech and Language Therapists and Early Years Education services.

During the Assessment

Discussion of concerns, strengths and difficulties and observation of the child Q3, Q4, Q5

All but one parent (96%) felt that their concerns were addressed and they were listened to.

Fifteen out of 24 (63%) parents felt that the observation of the child in the clinic was adequate and felt that the team had an accurate picture of the child.

Twenty two parents (92%) felt that their child's strengths and difficulties were discussed.

Receiving the Diagnosis

Usefulness of receiving the diagnosis Q6

For this question parents were asked to choose as many comments as they felt was applicable in describing their views about receiving the diagnosis for their child. When asked about the usefulness of receiving the diagnosis, 22 parents (92%) stated that they were relieved by the diagnosis. Many parents felt that receiving diagnosis made them accept and adapt to the child's behaviour better.

Ten parents out of 24(42%) felt that even after receiving the diagnosis it was difficult to get practical help for their child.

One parent commented that *'there was nothing useful about the diagnosis'*.

Another parent commented on the *'usefulness of the parent training course- Early Bird'*.

To address the questions about usefulness of and difficulties in receiving the diagnosis, the parents were asked to tick as many comments as they felt appropriate to describe their feelings of receiving the diagnosis.

| USEFULNESS OF RECEIVING DIAGNOSIS | AGREE | DISAGREE |
|---|----------|----------|
| Relieved the diagnosis had been made | 92%(22) | 8% (2) |
| Able to accept my child's behaviour | 71% (17) | 8% (2) |
| A better understanding of my child's behaviour | 83% (20) | 8% (2) |
| Other people had a better understanding of my child's behaviour | 50% (12) | 38% (9) |
| Able to adapt family life to my child's behaviour | 67% (16) | 21% (5) |
| It helped me stop blaming myself | 63% (15) | 25% (6) |
| Partner blaming himself or herself | 50% (12) | 33% (8) |
| Able to get practical help for my child | 42% (10) | 42% (10) |
| Able to get support for myself | 54% (13) | 8% (2) |

Table1: Usefulness of receiving the diagnosis Q6

Difficult about receiving the diagnosis Q7

Over half of the parents felt that they were more worried about their child's future. Just over 60% of parents stated that other people did not understand the diagnosis. Sixty seven percent of parents found it difficult to understand the patterns of behaviour in their child.

| Difficult about receiving the diagnosis | AGREE | DISAGREE |
|---|-----------------|-----------------|
| Shocked by the diagnosis | 21% (5) | 54% (13) |
| More worried about my child's future | 54% (13) | 25% (6) |
| Other people do not understand the diagnosis | 63% (15) | 25% (6) |
| My child has been treated worse by other people | 25% (6) | 54% (13) |
| Which problem behaviours are caused by the disorder and which are not | 67% (16) | 21% (5) |
| Other people reject the diagnosis | 33% (8) | 29% (7) |

Table 2: Difficult about receiving the diagnosis Q7

The following comments were made by parents about their feelings on receiving the diagnosis.

'A sense of grief, had no idea what ASD was; as it is a complex condition'

'Even when diagnosis was suspected it is difficult once it is confirmed, you have to come to terms with what it really means for your child and family'

'Teachers seem to think Autism is about problem behaviours and don't seem to understand Atypical Autism'

Explanation of the diagnosis Q8

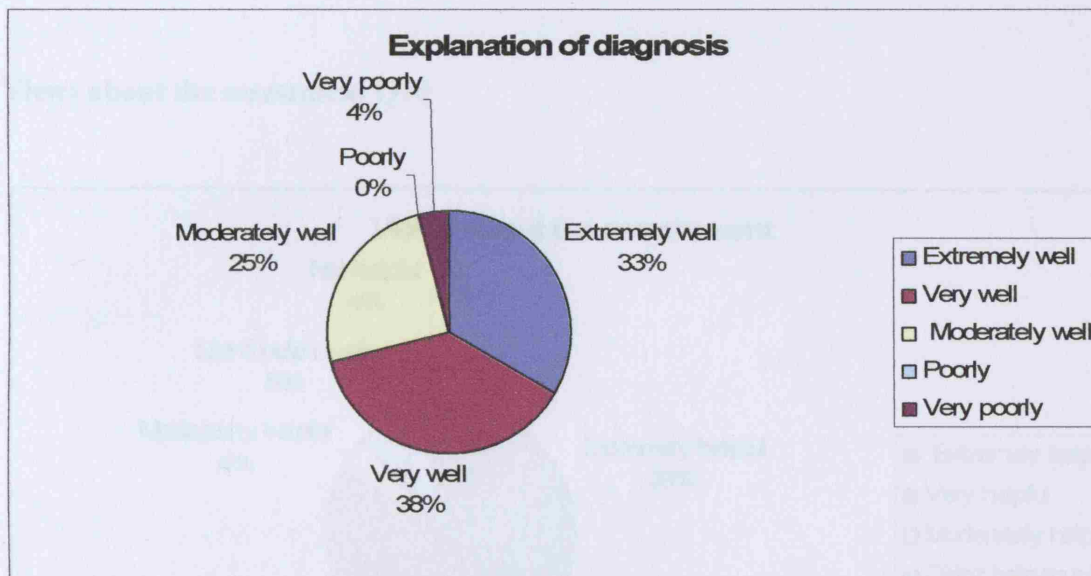


Figure 5: Explanation of the diagnosis Q8

Seventeen parents (71%) felt that it was explained extremely/very well. Six parents (25%) felt that the diagnosis was explained moderately well. One parent felt that it was very poorly explained.

Clear Plan after diagnosis Q9

Eleven parents (46%) stated that a clear plan was made following diagnosis. Eleven parents (46%) said that they were not aware of a plan. Two parents (8%) were not sure if a plan was made.

Views about the assessment Q10

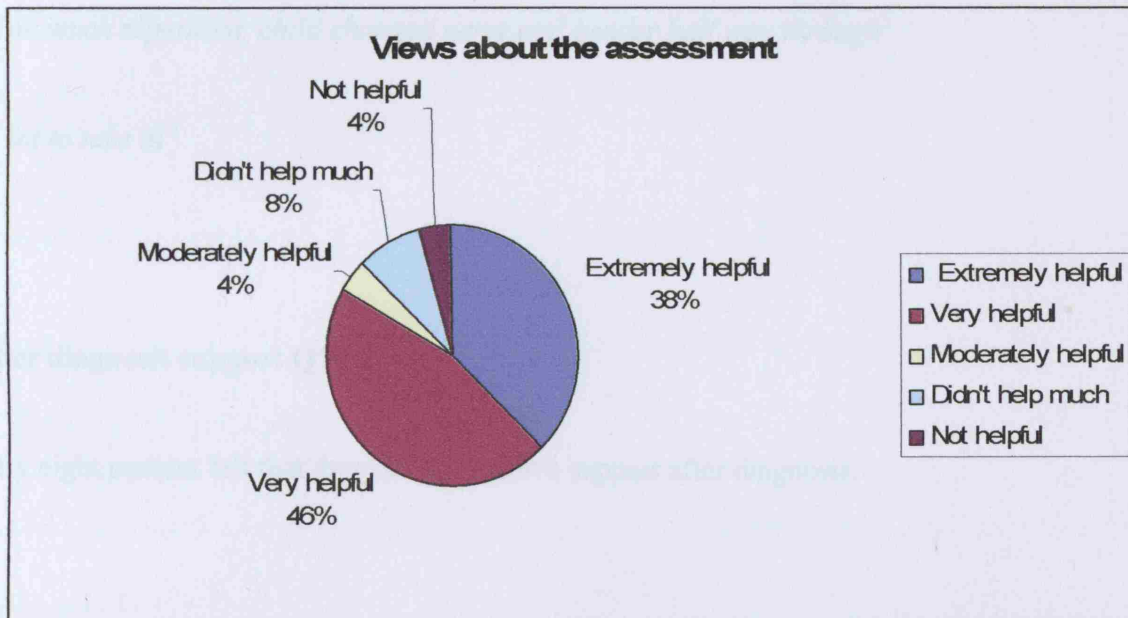


Figure 6: Views about the assessment Q10

Twenty out of twenty four (84%) parents felt that the assessment was extremely/very helpful. One parent (4%) felt that it was moderately helpful. Two parents (8%) felt that the assessment was not that helpful. One parent said that the assessment was not helpful.

After assessment

Quality of the report Q12

Nineteen parents (79%) felt that the reports were easy to follow, 2 parents (8 %) felt that it was difficult to read. Following are some of the comments parents made about the copy of the report.

'Too much repetition, child changed name and gender half way through'

'A lot to take in'

After diagnosis support Q14

Fifty eight percent felt that they did not receive support after diagnosis.

Parents were also asked about what they felt **was good about the assessment. Q17**

'Assessment was relaxed, my son was not stressed in any way, and they went at our pace'

'It seemed very thorough; all aspects of my sons development was discussed'

'Child focused'

'They had all information about my child beforehand and were very receptive of my own views'

'We had adequate time to discuss about the diagnosis'

'I was relieved that someone was listening to my concerns about my child'

'After years of living with my child's difficult emotions and behaviour I finally found someone to listen to me'

'I knew my child had autism from the age of 2, the clinic confirmed the diagnosis'

'My child had finally been diagnosed'

'Finally getting a diagnosis'

'It helped me understand my child more & explained a lot about his behaviour and why his peers treated him differently'

'Helped us know about what was wrong with our child, everything was good about the assessment'

'I knew all along my child's behaviour in some ways was different to other children the diagnosis confirmed it for me'

'Speech therapist visit to school was the only beneficial part to come out of the assessment'

'It laid down clear guidance; it explained how the decision was reached'

'It explained what was wrong with the child'

Parents felt that the team had a child and parent centred approach to assessment and felt that the team took the time to listen to their concerns about their child and were receptive to parents' views. They also felt that the team had all the information needed to inform the diagnostic process and felt that the assessments were thorough. The relief of receiving the diagnosis was evident in the parents' comments. The assessment helped parents understand their child's behaviour. The explanation of the diagnosis was clear and parents felt that the diagnostic process was transparent.

The following were the comments made for the question 'what was not so good about the assessment?' Q18

'The room was not nice, could have done more to make it comfortable for everyone'

'It was sometimes difficult to remember some of the things my son did or did not do as a baby; it may help to recommend to parents to prepare themselves prior to assessment, maybe with being given a list of possible topics that will be discussed'

'There were no other professionals out the other side to help with putting strategies/provision in place'

'The time it took'

'If the child is tired we can choose another day which can help the child to be concentrated'

'Just treated like another patient for the record'

'That no help can be given after my son goes to secondary school by the clinic. It took ages to conduct and get a diagnosis'

'Communication with the clinic i.e. getting through to the doctors was at most times impossible'

'Waiting time to get assessed'

'I felt uncomfortable answering questions with my child listening. I felt sorry for him because he was left with the impression that something was wrong with him'

There were a few comments about the clinic setting; one parent would have liked a more comfortable setting. The frustration of not having any support after the diagnosis was evident. Many parents rightly raised the issue of long waiting lists leading to a delay in the diagnosis. Some parents felt that the access to advice and support from the doctors was difficult.

Eight percent of the parents were dissatisfied with the assessment and they made **specific suggestions.Q20**

'I believe most people can cope with a diagnosis if given the necessary back up. However I have heard from no one since the diagnosis was made, and it was down to me to chase up the reports. My main concern was my son's education and the clinic's diagnosis has not had any bearing on this matter. I believe an individual liaison officer similar to a health visitor to guide parents on all matters arising from child's diagnosis would be beneficial. I would have liked to have a person like a specialist nurse for e.g. to discuss anything big or small, relevant or irrelevant; someone, who would support my child and ourselves and discuss any concerns. It is an all round caring approach that makes a difficult life considerably easier. This kind of support from the communication clinic would be invaluable; someone who sits on the clinic and is therefore providing a coordinated approach both medically and with support. I have to say I felt 2 years waiting for a diagnosis and that being the endpoint of the service seems pointless'.

'More information while on waiting list, greater sharing of information between professionals and parents, had no idea that child was seen by Speech and Language Therapist at school'

'Appalling unhelpful attitude of admin staff. The Communication Clinic did not engender any feeling of trust, hence questions the validity of the diagnosis'

'Improve the time scale, link to other services for information, suggest meet up with other parents and children, more info also need to be given to the school and training'

'Follow up meeting should include education'

'Improve appointment time, more Speech and Language Therapy, support parents with resources'

'I think once the children's centre opens and all the services are combined waiting lists will reduce and communication between teams of professionals will improve'

'It should be less waiting time and more help for parents to get referred as I did not get my son's diagnosis until he was 11 years old after years of teachers saying he was naughty'

'Better surroundings, more information before hand .Follow up consultations afterwards, maybe one or two if needed. Better help for children their education especially who are diagnosed late'

'Improve waiting time'

'Everything has a long waiting list'

'Screen patients prior to assessment, home visits/school observations'

'Now that diagnosis has been made, not sure what's next or is that it'

'I don't think having my child sit through the assessment listening had really helped his self esteem'

There was dissatisfaction with the delay in diagnosis and the after diagnosis support and suggestions were made to shorten waiting list and offer support to parents following diagnosis. One parent raised the issue of key working and after diagnosis and ongoing support. They wanted greater information sharing between agencies and felt the diagnostic process should involve all the agencies including education. There were suggestions to improve access to services especially speech therapy.

Overall Satisfaction Q19

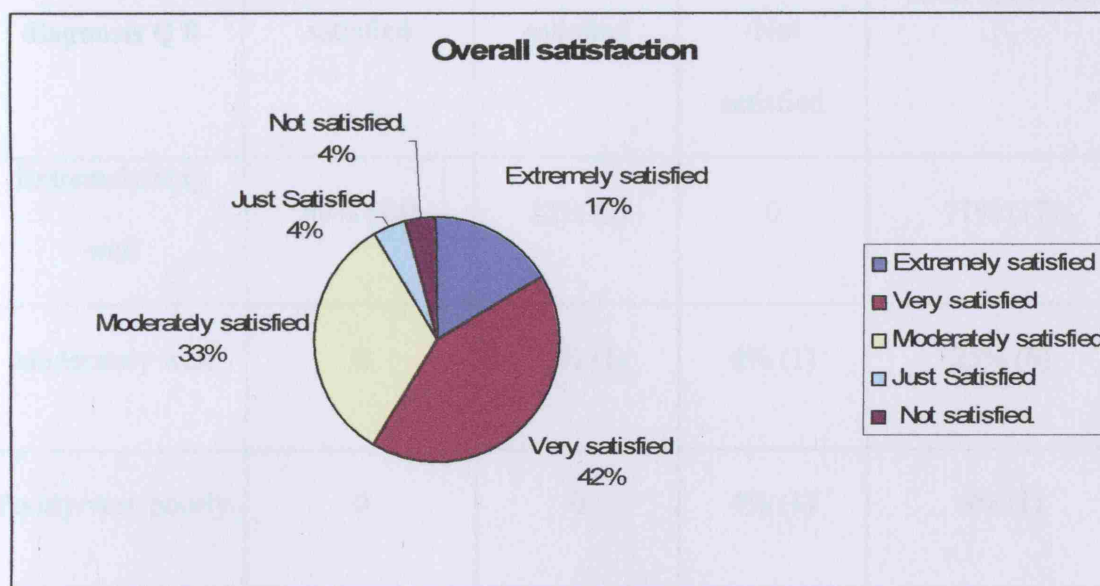


Figure 7: Overall satisfaction Q19

Fourteen (59%) parents were extremely/very satisfied; eight (33%) parents were moderately satisfied with the overall services. Two(8%) parents were not satisfied with the services.

Comparison of explanation of diagnosis and overall satisfaction

| Overall satisfaction Q 19 | | | | |
|-------------------------------------|---------------------------------|-----------------------------|--------------------------------------|------------------------|
| Explanation of diagnosis Q 8 | Very/Extremely satisfied | Moderately satisfied | Just satisfied /Not satisfied | Total responses |
| Extremely/very well | 59% (14) | 12% (3) | 0 | 71% (17) |
| Moderately well | 0 | 21% (5) | 4% (1) | 25% (6) |
| Poorly/very poorly | 0 | 0 | 4% (1) | 4% (1) |
| Total responses | 59% (14) | 33% (8) | 8% (2) | 100% (24) |

Table 3: Explanation of diagnosis and overall satisfaction Q8, Q19

Majority of parents who felt that the diagnosis was explained extremely/very well were also very/extremely satisfied.

Comparison waiting time and overall satisfaction

| Waiting time Q1 | Overall Satisfaction Q19 | | | |
|--------------------|-----------------------------|-------------------------|----------------------------------|-----------------|
| | Very/Extremely satisfied | Moderately satisfied | Just satisfied /Not satisfied | Total responses |
| Too soon | 0 | 0 | 0 | 0 |
| Just right | 0 | 4% (1) | 4% (1) | 8% (2) |
| Much too long | 59% (14) | 29% (7) | 4% (1) | 92% (22) |
| Total responses | 59% (14) | 33% (8) | 8% (2) | 100% (24) |

Table: 4 Waiting time and overall satisfaction Q1, Q19

Over half of the parents who stated that the waiting time was too long were very satisfied with the services.

Comparison of age at diagnosis and overall satisfaction

| Age at diagnosis | Overall satisfaction Q19 | | | |
|------------------|--------------------------|----------------------|-------------------------------|----------|
| | Extremely/very satisfied | Moderately satisfied | Just satisfied /Not satisfied | Children |
| under 5 years | 17%(4) | 0 | 0 | 17%(4) |
| 5-10 years | 42%(10) | 4%(1) | 4%(1) | 50%(12) |
| 10-15 years | 0 | 29%(7) | 4%(1) | 33%(8) |
| Total responses | 59%(14) | 33%(8) | 8%(2) | 100%(24) |

Table 5 : Comparison of age at diagnosis and overall satisfaction

All parents whose children were diagnosed before the age of 5 years were extremely/very satisfied. Ten out of 12 parents whose children were diagnosed between 5 and 10 years of age were very satisfied. None of the 8 parents of children who were diagnosed after the age of 10 years were very satisfied.

Comparison of views about the assessment Q10 and overall satisfaction Q 19

| Views about assessment Q10 | Overall Satisfaction Q19 | | | |
|----------------------------|--------------------------|----------------------|-------------------------------|-----------------|
| | Extremely/very satisfied | Moderately satisfied | Just satisfied /Not satisfied | Total responses |
| Very helpful | 51% (12) | 8% (2) | 0 | 59% (14) |
| Just helpful | 33% (8) | 0 | 0 | 33% (8) |
| Not helpful | 0 | 4% (1) | 4% (1) | 8% (2) |
| Total response | 84% (20) | 12% (3) | 4% (1) | 100% (24) |

Table 6; Views about the assessment and overall satisfaction Q10, Q19

Twelve out of fourteen parents who felt that the assessment was very useful said that they were very satisfied.

Responders vs. Non responders

As the response rate was very low, data regarding the family status, time on the waiting list for the Communication Clinic, post code, age at diagnosis and co morbidities were collected. Attempts at collecting data on ethnicity, age and occupation of parents proved to be futile as these were not consistently recorded in the notes. The child development service has a voluntary ethnicity monitoring procedure and less than 20% of the notes had information on ethnicity. Some of the reports and doctor's notes had the country of origin of parents and again this was inconsistently recorded.

| Family status | Responders | Non responders |
|----------------------|-------------------|-----------------------|
| SINGLE | 25% (6) | 69% (38) |
| 2-PARENT | 75% (18) | 31% (17) |
| Total | 100% (24) | 100% (55) |

Table 7: Family status of responders and non responders

There were nearly 70% of single parent families among the non responders compared to only 25% single parent families among responders. Majority of the parents in the responders group were from a 2 parent family.

| Waiting time | Responders | Non responders |
|-----------------------|-------------------|-----------------------|
| 6 months | 8% (2) | 0% (0) |
| 7-11 months | 8% (2) | 5% (3) |
| 12 months - 18 months | 63% (15) | 94% (51) |
| 18 months and over | 21% (5) | 1%(1) |
| Total | 24 | 55 |

Table 8: Time on waiting list for the communication clinic for responders and non responders

Majority of the parents whose children waited for between 12- 18 months did not respond.

| Postcode | Responders | Non responders |
|---------------------|-------------------|-----------------------|
| Most deprived | 33 %(8) | 58% (32) |
| Moderately deprived | 50%(12) | 31% (17) |
| Least deprived | 17%(4) | 11% (6) |
| TOTAL | 24 | 55 |

Table 9 : Post codes of responders and non responders

It appears that, twice as many non responders compared to responders were from the least deprived wards of Lewisham. Sixty seven percent of the responders were from moderately and least deprived postcodes compared to 42% of the non responders.

Validation

| Answers | Same info from notes and questionnaire | Different info from notes and questionnaire |
|---------------------------|---|--|
| Follow up Q12 | 17 | 7 |
| Copy of report Q11 | 24 | 0 |

Attempts to validate the answers given to question Q11 and Q12 were made by comparing this with the information available in the case records. All the 24 parents who had a copy of the report agreed that they received a copy of the report. All the 24 parents were followed up but only 17 out of 24 agreed that they were seen for a follow up appointment.

DISCUSSION

Parental perception of services

The results of the study suggests that majority of the parents were satisfied with the overall services. It was quite surprising that parents were satisfied with the services despite the long waiting time for the assessment and consequently the delay in diagnosis. It seems that there were other factors such as the child centred approach to the assessment, the way the diagnosis was explained, the relief of finally receiving the diagnosis, having a clear plan and receiving a copy of the report have influenced parent's satisfaction. The dissatisfaction with the long wait for the diagnosis seems to have been negated by these factors. Parents also raised the issue of support following the diagnosis. Over half of the parents were not satisfied with the after diagnosis support. Parents of children who were diagnosed before their fifth birthday were very satisfied.

In a survey of parents of 1200 families of children with ASD Howlin et al studied various factors that influenced parent satisfaction with the diagnostic process. Satisfaction appeared to be affected by the length of time the parents had to wait before receiving a diagnosis⁴³. Clear associations were noted between the diagnosis given and parental satisfaction. Unequivocal diagnoses of Autism, Asperger Syndrome were more acceptable than less discrete entities.

In this study some parents who felt that the waiting time was too long were very satisfied with the services. It is possible that parents in this study felt satisfied overall even though they had to wait for an average of 12 months before the child was diagnosed because their views might have been influenced by other factors in the assessment.

Early diagnosis is still relatively rare despite major advances over the recent years in understanding the nature of ASDs^{29 38}. Positive experience of diagnostic procedures significantly influences parents' satisfaction. Many parents of children with Autism are far from satisfied⁷⁵. Obtaining a diagnosis is particularly difficult if the difficulties are subtle as in the higher functioning or the Atypical Autism compared to children with more obvious difficulties with language and cognition.

Early diagnosis ensures that the interventions are implemented early. There is increasing evidence that early interventions are effective and may prevent secondary behavioural difficulties. Delay in diagnosis impedes appropriate educational input and support for the children. It also has wider implications for siblings and families.

Majority of parents in this study felt that they were listened to and their child's strengths and difficulties outlined. Many parents were also satisfied with the way the diagnosis was

explained. One parent stated that she doubted her child's diagnosis and said that she did not agree with the team.

Many parents felt that the multidisciplinary team had the opportunity to observe the child in clinic and stated that the team had an accurate picture of the child. Some parents suggested that the clinic setting was quite artificial and that the child has to be observed in different settings. It is also recommended by the NIASA working party that the child has to be observed in different settings³⁵. Although the members of the team may not have observed the child in different settings, some of the children would have been observed in educational settings and at home by various members of the team who would have contributed reports towards the assessment. It was quite surprising to see one of the parent's comments that they were not aware that their child was seen by the Speech therapist in the nursery. This raises the issue of consent and transparency in the assessment process.

No parent is really prepared to hear the news that there is something wrong with their child, whether the news of disability comes suddenly or after a period of time. The response in this study and other studies has shown parents' relief on getting their child diagnosed^{76 77}. One can't begin to imagine the distress and frustration the family goes through in trying to get their child's problems recognized. The relief stems from the fact

that someone has finally listened to them and taken their concerns seriously. Majority of the parents stated that they were relieved by receiving the diagnosis.

Many parents also felt that they were able to accept and adapt to their child's behaviour. However half of the parents felt that they had not received any practical help or support after diagnosis. In a survey of parents perception of tertiary diagnostic services it was found that parents felt strongly about the after diagnosis support with behavioural management and other practical help⁷⁸. Piper and Howlin pointed out that although clear diagnostic information and advice for parents are invaluable they are still insufficient as most families also require practical help and support to learn and implement management advice⁷⁹.

Some parents felt that other people did not understand the diagnosis and there is still some paucity of knowledge among educational staff about the wider autistic continuum.

There was an overwhelming feeling that the support offered after diagnosis was inadequate and there were suggestions that they needed practical help and input into education. One parent also reiterated the importance of having a key worker to coordinate, signpost and support the family after diagnosis and offer ongoing support.

Just having someone to talk to in times of need or clarify issues or just knowing that there is a person to contact is immensely helpful as one parent put it.

The increased demand on the Child Development Service for assessment, diagnosis and management of children with ASD mirrors research findings nationally and internationally and service experience in other UK districts. The rapid increase in awareness of ASD and under-recognition in previous years has contributed to a steady rise in referrals for assessment and demands on intervention services. Service provision and resources have not remotely matched need. The Communication Clinic has attracted ever-increasing referrals, as the reputation of the service has grown and as ASD awareness has increased amongst professionals in Health, Early Years and Education, and amongst parents.

Many children whose needs were not recognised or were categorised in a different way in the past, are now requiring specific ASD assessment, diagnosis and intervention. Their needs are complex and lifelong. Meeting these needs is an inter-agency task for child health and mental health services, education, social care, and the voluntary sector. In the last 6 years many more children are being referred in a concentrated period, reflecting the recent greater awareness in Lewisham. Current referrals consist therefore of both expected numbers of under 5s and late referrals of older children. The referral to the Communication Clinic has steeply increased from 58 per year in 2000 to 183 in 2004,

with a 3 year average of 162 referrals per year. The pressure on the service from increase in referrals has led to an extended waiting time, despite recent investment and more than doubling of clinics. Various measure have already been put in place to improve services

Regular training sessions help extend knowledge and competence to other members of the medical and Speech & Language Therapy teams. Further ad hoc additional communication clinics have since been arranged with Communication Clinic Service members joining other professionals to help them with a child's assessment. Lewisham Education has been approached to consider their involvement in the diagnostic service and to work to build more integrated approaches to intervention. The Lewisham Autism Service, started in 2003 and supported by joint funding and managed by the National Autistic Society gives early support to families of newly diagnosed children and provides limited crisis intervention.

Limitations of the study

Non Response

Various measures were undertaken to reduce the expected reduced response rate; the personalised invitation letters, self addressed envelope and a simple piloted questionnaire. These were sent after cross checking with GP records to ensure that the questionnaires were sent to the right people at the right address. The study was mentioned in the Local Parent Group newsletter in June 2004. No questionnaire was sent back due to dispatching to a wrong address. Despite all these measures the response rate was disappointingly low. Ethical approval was sought for telephone follow up of non responders but was denied. Due to the poor response rate the case records of all the 79 children were examined to compare responders (30%) and the non responders (70%).

Non response may have been due to various reasons.

The questionnaire was posted in the second week of July a week before schools in Lewisham closed for the summer holidays. The reminders were sent two weeks later in August. Due to the school holidays many families may have been on holiday. Even if they were around we only know too well how busy family life can be during school holidays and can be particularly difficult for parents with dependent children with special needs.

Parents may have been either very satisfied or very dissatisfied with the services. Non response itself may indicate their negative attitude or bad experiences with services although one cannot assume that.

The non responders may have been from a lower socio-economic status (as the results suggest) or may have more stressful lifestyles. Illiteracy and language may have played a role. There are 120 languages spoken in Lewisham and hence it was not feasible to translate the questionnaire. Looking through the notes it was noted that none of the 79 children were seen with an interpreter. However one cannot assume that all parents had the ability to read and fill in the questionnaire irrespective of the fact that they were able to speak English.

Some parents may have felt uncomfortable about complaining or giving negative feedback especially if they have ongoing and regular contact with Communication Clinic team although it was made very clear in the information sheet that the child's care will not be affected and their anonymity will be preserved.

The low response rate introduces selection bias and hence threatens the external validity of the study. The responders' views may not be representative of all the parents of children who were diagnosed in the Communication Clinic. It is likely that the parents

who responded felt quite strongly about their views about the Communication Clinic and had wanted to provide feedback and had the ability to do so. These might be the parents who have the means and ability to try and meet their child's needs (one parent suggested that she had to try and ring a few times to chase up the reports). The inverse care law suggests that the most in need have the least access to services. As in any postal survey one can never be sure that the information given by parents represents exactly how they feel.

Recommendations

1. Measures to reduce waiting list for the Communication Clinic

Various measures have already been implemented to reduce waiting time. Depending on the concerns the child can either go through general developmental assessment or if diagnosis is obvious and parents have suspected the diagnosis the child can be fast tracked for multi disciplinary and multi agency assessment. Flexibility in services to allow children take a quicker route to diagnosis. Continuing audits of waiting lists is essential to monitor this. Redesigning and or increase in resources should address the important issue of delay in diagnosis

2. Post diagnosis /Ongoing support

A good signposting system helping parents have access to information and support needs to be developed. The services should not stop with diagnosis or period of intervention. Children should have ongoing access to services. Their needs change as they grow because ASD is not a static condition. It is well recognised that there are psychiatric co morbidities associated with ASD. The services should be able to offer lifelong support for a lifelong disorder. Care coordination /key working is invaluable in facilitating and supporting children and parents.

3. Multi agency assessments

NSF recommends that an integrated multi agency, multidisciplinary approach to assessment, intervention and support should underpin services for children with complex needs. Parents had pointed out the need for multi agency involvement and that local education authority should be part of the assessment process. All the relevant agencies and services have to contribute towards the assessment and diagnostic process, leading to needs led, child and family focused care plan and interventions. With the new children's centre housing all the relevant agencies such as child health, CAMHS, social care and education under one roof will be a great leap towards a child and family centred service as recommended by the ECM⁵⁵.

FURTHER RESEARCH

Services should continue to evaluate and incorporate children and young people and their families' views in planning and delivery of needs led child and family centred services. Appropriate methods of data collection and measures need to be implemented in order to ensure that the views are representative of the population being studied.

Interviewing parents would have provided the opportunity to validate the questionnaire. The response rate would have been better if the questionnaire was administered after the follow up appointment in the clinic. More in depth interviews with parents would have helped to further explore parental perception of services.

Joint research with education, health and social care would be invaluable to evaluate not only the diagnostic processes but also to monitor access to different services and to identify gaps in service provision for these children.

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APPENDIX 1 Invitation letter

Dear (Parent/Carer)

Re:-Survey of Parental Views of Services offered by the Communication Clinic in Priory Manor Child Development Centre, Lewisham, for Children with Autism Spectrum Disorder

I am writing to invite you to participate in a survey after discussions with your Community Paediatrician at Priory Manor Child Development Centre, Lewisham. We want to find out what Parents/Carers feel about services offered by the Communication Clinic for children with Autism Spectrum Disorder.

Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the attached information sheet carefully.

If you decide to take part, please fill in the enclosed Parent /Carer consent form and the questionnaire and return them in the prepaid self addressed envelope within the next 2 weeks. Please do not hesitate to contact me if you have any queries or if you need more information.

I can be contacted at the above address. Alternatively you could phone or email me.

Phone: 020 7414 1450

Email: brindha.dhandapani@lambethpct.nhs.uk

Thank you.

Yours sincerely,

Dr. Brindha Dhandapani.

APPENDIX 2 Questionnaire

QUESTIONNAIRE OF PARENTAL VIEWS ABOUT THE SERVICES OFFERED BY THE COMMUNICATION CLINIC AT LEWISHAM

Your child attended Communication Clinic at Priory Manor Child Development Centre for assessment.

Please answer the following questions about your experience with this service.

For each question please tick the box next to the answer which best describes your view and write in more detail where asked.

PRE-ASSESSMENT

1. How do you feel about the waiting time for the Communication Clinic appointment?

- Much too long
- Too long
- Just right
- Too soon
- Much too soon
- Don't know

2. a) While on the waiting list did you receive any leaflet about the communication clinic/ Priory Manor Child Development centre?

- Yes, If so was it useful? Yes No
- No If it wasn't useful, what kind of information would you have liked

.....

b) While on the waiting list did you receive any support from the team for example Doctors, Speech and language therapist, Health visitor?

- Yes
- No If no, what support would you have liked

.....

COMMUNICATION CLINIC ASSESSMENT

3. Did you feel you had been listened to and your concerns about your child had been taken into account during the assessment?

- Yes
- No
- Don't know
- Other

4. Did you feel/think the team had an accurate picture of your child in the clinic?

- Yes
- No
- Don't know
- Other

5. Were your child's strengths and difficulties discussed?

- Yes
- No
- Don't know
- Other

I would like to find out what you found useful or difficult about finding the diagnosis. Please read the statements and show if you agree or disagree with each. Please tick as many boxes as applicable.

6. What did you find useful about receiving the diagnosis?

Agree Disagree

- I was relieved the diagnosis had been made
- I have been able to accept my child's behaviour
- I have a better understanding of my child's behaviour
- Other people have a better understanding of my child's behaviour
- We have been able to adapt family life to my child's behaviour
- It helped me stop blaming myself/ partner blaming himself or herself
- I have been able to get practical help for my child
- I have been able to get support for myself

- Other

7. What did you find difficult about receiving the diagnosis?

Agree Disagree

- I was shocked by the diagnosis
- I have become more worried about my child's future
- Other people do not understand the diagnosis
- My child has been treated worse by other people
- It is difficult to know which problem behaviours are caused by the disorder and which are not
- Other people reject the diagnosis

- Other

8. What are your views on how the diagnosis was explained to you?

- Extremely well
- Very well
- Moderately well
- Poorly
- Very poorly

9. Was there a clear plan for your child after the assessment?

- Yes
- No
- Don't know

10. What are your views about the assessment?

- | Agree | Disagree | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | It was extremely helpful |
| <input type="checkbox"/> | <input type="checkbox"/> | It was very helpful |
| <input type="checkbox"/> | <input type="checkbox"/> | It was helpful |
| <input type="checkbox"/> | <input type="checkbox"/> | It didn't help much |
| <input type="checkbox"/> | <input type="checkbox"/> | It was not helpful |

AFTER ASSESSMENT

11. Did you receive a copy of the report?

- Yes
- No
- Don't know

12. What are your views about the quality of the written report?

- Easy to follow
- Difficult to read
- Other

If difficult, please describe why

.....

13. Did the team refer your child to other agencies?

- Education
- Disability Social Worker
- Lewisham Autism Support
- Genetics
- Others (please describe).....
- Behavioural support
- Occupational Therapist
- Special Needs Health Visitor

14. Did you feel you received enough support from the Communication Clinic team once the diagnosis was made?

- Yes
- No
- Don't know

15. Were you and your child seen by the Communication Clinic team for a follow appointment to discuss diagnosis and report?

- Yes
- No
- Don't know

16. Was a nursery/school or home visit made by one of the team members before or after the assessment?

- Yes
- No
- Don't know

SUMMARY

17. What did you think was good about the assessment?

.....

.....

.....

.....

18. What did you think was not so good about the assessment?

.....

.....

.....

.....

19. Overall how did you feel about the service?

- Extremely satisfied
- Very satisfied
- Satisfied
- Just Satisfied
- Not satisfied.

20. Do you have any suggestions to improve current practice? (Please describe)

.....

.....

.....

.....

.....

.....

Please indicate below if you would agree to be interviewed on the phone by the researcher:-

- Yes No Possibly (would like more information)

If yes when would you prefer to be contacted?

Day Time

Thank you very much for taking time to fill in the questionnaire.

Please remember to post this form to me in the envelope provided.

APPENDIX 3 Information sheet

INFORMATION SHEET

TITLE

Survey of Parental Views of Services offered by the Communication Clinic for Children with Autism Spectrum Disorder.

Invitation

You are being invited to take part in this survey. Before you decide, it is important to understand why the survey is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

What is the purpose of the survey?

We would like to find out what parents feel about the services offered by Communication Clinic for children with Autism Spectrum Disorder (Autism, Asperger's syndrome, Atypical Autism, Pervasive Developmental Disorder) in Lewisham, as it was felt that, this was a subject that had not been previously looked at in Lewisham. The result will help us find out what Parents/Carers think of current services and if there are any areas for improvement. We hope that this survey will help improve services for children with Autism in the future, taking into consideration the views of parents.

Why have I been chosen?

We are sending questionnaires to Parents/Carers of children who were diagnosed with Autism Spectrum Disorders during the period between January – December 2004. We are looking to survey about 100 Parents/Carers.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you will be given a copy of this information sheet to keep and be asked to sign a consent form. You will also be given a copy of the consent form to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care your child receives.

What do I have to do to take part?

At this stage taking part involves filling in the questionnaire. However we would also like to interview a few of those taking part in the survey. The interview may be done by telephone. Please tick the box at the bottom of the consent form to show whether you would be willing to be interviewed.

If you consent to take part in the survey, your child's medical records may be inspected by the researcher for purposes of analyzing the results.

Will my taking part in the survey be kept confidential?

All information you give us will be kept strictly confidential. This means no names and addresses will be on the questionnaire. Names and addresses will be kept separate from the questionnaire. In the final report there will be no way of identifying any personal details. As it is usual practice to inform your GP, he/she will be notified of your participation in the research.

What will happen to the results of the survey?

If the results of the survey are published in a medical journal you will not be identified in any report/publication. The report will also remain in the Institute of Child Health, where the Masters Course is being conducted.

Who is organizing and funding the survey?

The doctor conducting the study is not being paid to do the research. She is conducting the survey as part of a Masters degree.

Who has reviewed the survey?

The survey has been reviewed by Lewisham Research Ethics Committee.

Contact for further information

She would be happy to answer any questions you may have. Please feel free to contact her at/on:

Dr. Brindha Dhandapani
Mary Sheridan Centre for Child Health
5 Dugard Way Off Renfrew Road
Kennington
London
SE11 4TH
Telephone: 020 74141450
Email: brindha.dhandapani@lambethpct.nhs.uk
Thank you for taking time to read the information.

15.07.05

APPENDIX 4 Reminder letter

29th July 2005

Dear

Re :- Survey of Parents' Views of the Services offered by Communication Clinic for children with Autism Spectrum Disorder.

Approximately two weeks ago I invited you to take part in a survey. At the time of sending this letter we have not had a reply from you.

I am writing again to invite you to take part in a survey. Your child was seen in the Communication Clinic, at Priory Manor Child Development Centre in 2004. We want to find out what Parents/Carers feel about services offered by the Communication Clinic for children with Autistic Spectrum Disorder.

Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the attached information sheet carefully.

If you decide to take part, please fill in the enclosed Parent /Carer consent form and the questionnaire and return them in the prepaid self addressed envelope within the next 2 weeks. If you have already returned your questionnaire, thank you and please accept our apologies for troubling you.

Please do not hesitate to contact me if you have any queries or if you need more information.

I can be contacted at the above address. Alternatively you could phone or email me.

Phone: 020 7414 1450

Email: brindha.dhandapani@lambethpct.nhs.uk

Thank you.

Yours sincerely

Brindha Dhandapani

APPENDIX 5 Letter to GP

Dear Dr.

I am writing to inform you that your patient has been invited to participate in a study of parental perception of services offered by the Communication Clinic in Priory Manor CDC for children with Autistic Spectrum Disorder. This will be part of my research project for my MSc in Community Paediatrics. It involves parents filling in a questionnaire. Please do not hesitate to contact me if you have any questions. Thank you.

Yours sincerely

Dr.Brindha Dhandapani

APPENDIX 6 Consent form

PID:

PARENT/ CARER CONSENT FORM

Title of the Project

Questionnaire Survey of Parental Views on the Services Offered by the Communication Clinic in Priory Manor Child Development Centre, for Children with Autism Spectrum Disorder

Name of Researcher : Dr. Brindha Dhandapani

Please complete this form if you wish to take part in the survey.

- What is your relationship to the child?
- Parent
 - Step- Parent
 - Carer

Please initial box

1. I confirm that I have read and understood the information sheet dated 15.07.05 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care and legal rights being affected.
3. I understand that sections of my child's medical notes may be looked at by the researcher where it is relevant to my taking part in research. I give permission for the researcher to have access to my child's records.
4. I agree to take part in the above study.
 - a) Questionnaire Survey
 - b) Telephone interview

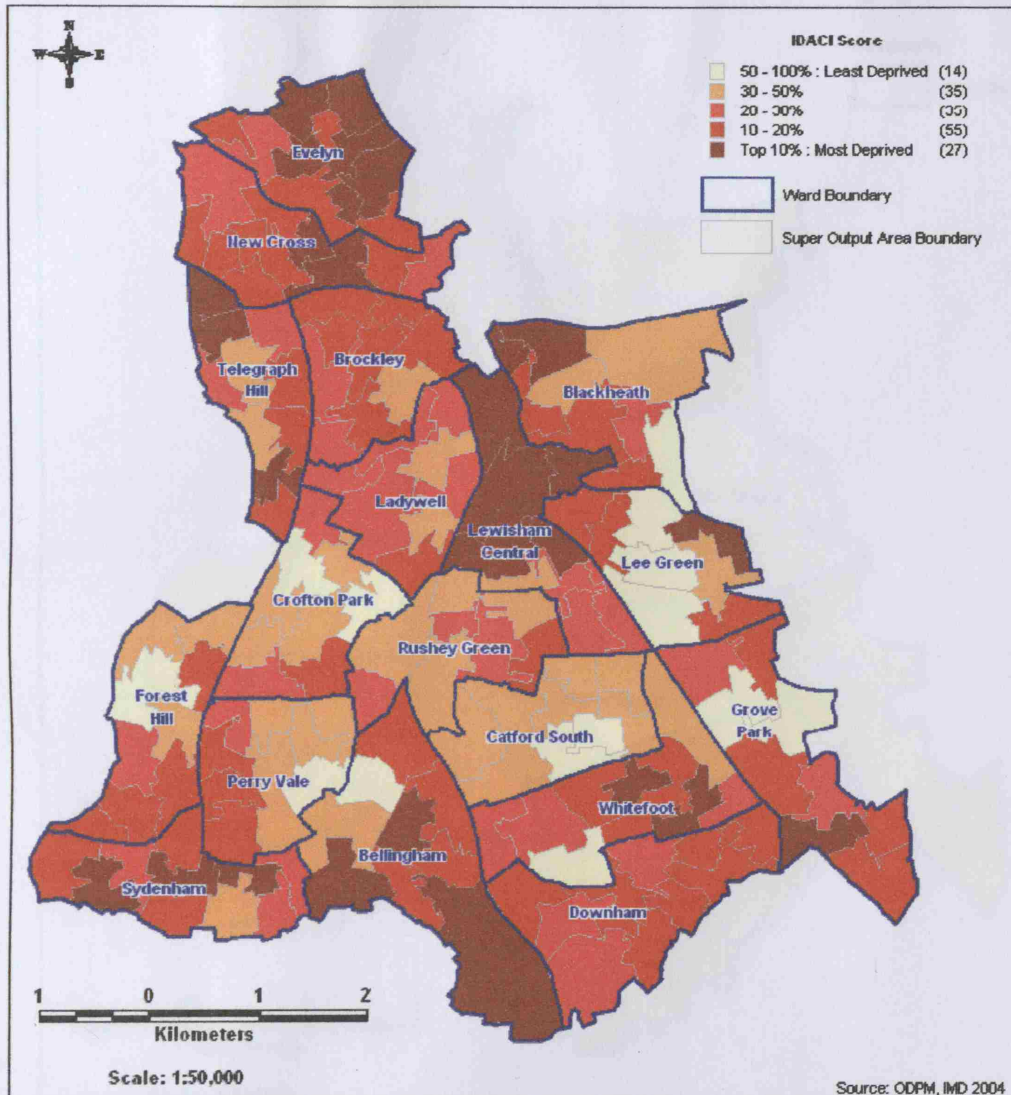
Signed:.....

Date

NAME(IN BLOCK LETTERS)

1 for Parent/Carer; 1 for Researcher; 1 for the Notes

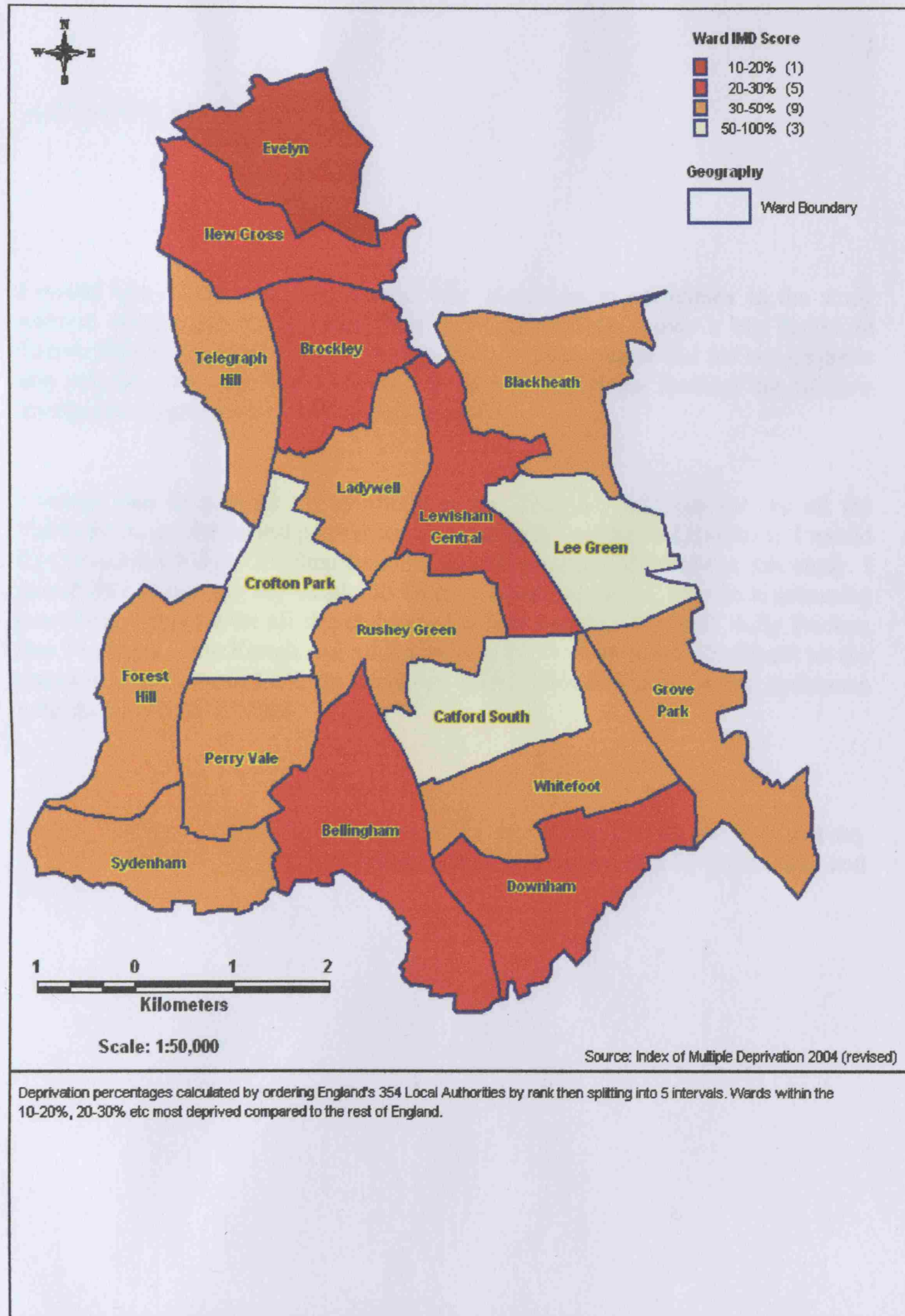
Income Deprivation Affecting Children, Lewisham 2004



Based on Income Deprivation Affecting Children Index (IDACI), Index of Multiple Deprivation 2004.

IDACI percentages calculated by ordering England's 32482 SOAs by rank and grouping SOAs into 5 intervals. (top 10%, 10-20%, 20-30% etc most deprived compared to the rest of England).

Deprivation. Index of Multiple Deprivation 2004 Lewisham Wards



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Finally I would like to dedicate this study to my family; my parents and my brother for all the support, my husband and my boys for their immense love and patience.