

# **Evaluation of the Key Worker Service for Families with Children Diagnosed with Autism Spectrum Disorders in County Durham**

**Helen Geldard. RGN. RM. MA. Education Studies and Autism.  
Development Worker for Families with Children with Autism Spectrum  
Disorders  
Sure Start, Durham.**

## **Acknowledgments**

I would like to say a huge thank you to the families and professionals who supported my role and gave their time to in order to provide the invaluable data to evaluate this project.

I would also like to that my work colleagues within the SureStart Inclusion Team for their help and advice throughout the project. Their expertise and experience is second to none.

A special thanks also to Jenny O'Neill for her support, advice and faith in me.

## **Findings of the Report:**

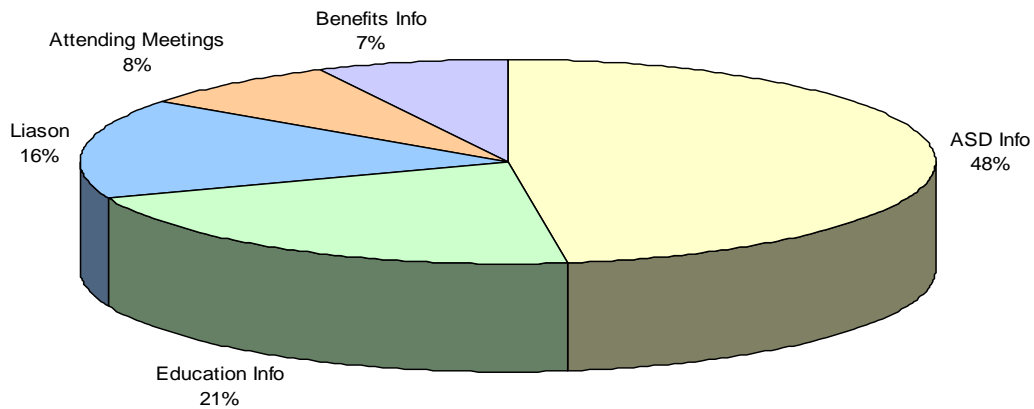
### **Evaluation of the Key Worker Service for Families with Children Diagnosed with Autism Spectrum Disorders in County Durham**

This role was developed within a framework following previous good practice and current developing practice from Every Child Matters (ECM). The project was based around the six elements of key working (Mukherjee et al 1999) but then interestingly naturally developed to meet the descriptors of the role within ECM (DfES 2006).

The Lead Professional Good Practice Guidance (2006) refers to the 'key worker' role for families with children with complex disabilities. This project was around supporting the needs of families with children diagnosed with Autism Spectrum Disorders (ASD) which fits the guidance descriptor of 'key worker' rather than that of 'lead professional' which is a role to be provided for all children.

Within the context of the project a single point of contact was established for families with referral being generated for a number of reasons and from various referral routes. All the responding families found the service of value. To ensure provision of 'appropriate interventions' a specific group of families, those with children diagnosed with or undergoing assessment of ASD were supported. From evaluation the highest level of support provided was ASD specific indicating the appropriateness of this provision. All responding families felt that they had received the support and help they needed in a way which was appropriate to them.

Family Support By Key Worker (Shown in Categories)



Evaluation highlighted a positive impact on the role of other professionals. This is described within the Lead Professional Good Practice Guide (2006) however more in-depth research is necessary. The aim of this report is therefore to further inform the development of guidelines for key working for families with children with all disabilities living within County Durham building upon the good practice guidelines published in 2006 by the DfES.

Influenced by Together from the Start 2002, the National Autism Plan for Children 2003 and the National Service Framework for Children 2004 the project aimed to deliver training to improve professional knowledge and skills so that professionals working with families have the right knowledge and skills to do the job. Joint training was delivered in conjunction with other established teams of professionals and evaluation was excellent.

The project was evaluated by seeking the opinions of families and professionals and through data collection from the project case load. The content of the full report aims to support the development of key worker roles within County Durham for children with complex disabilities.

Within the limitations of the project evaluation also showed development and maintenance of partnership across agencies.

The greatest number of referrals to the service came from the agreed route via the Child Development Team however 19% of the families supported by the service self referred indicating that this was a service they desired and needed (Sloper 1999, Mukherjee et al 1999, DfES 2002, DfES 2003, NAP-C 2003, DfES 2004). These families often needed the highest level of support.

Further consideration will need to be made with regard to referral routes and how this is formalised although data indicates that there should be an open referral route for families hopefully preventing families from getting to a point of 'crisis' (Every Child Matters (ECM)2005, Together from the Start 2002(TftS, The National Children's Service Framework (NCSF) 2004 & Removing Barriers to Achievement 2004).

Families of younger children required the greatest levels of support which again is supported by TftS 2002, ECM 2003, NAP-C 2003 and the NCSF 2004 which discuss the need for early intervention and support for families with children with disabilities. Families within the study had on average 6 professionals involved with them with the highest levels of professional input (many from Education and Health professionals) being around 0-3yrs and 10-11yrs when children were undergoing assessment or transition. Lead Professional Good Practice Guidance (DfES 2005) states that times of assessment and transition should always reflect higher levels of co-ordinated professional support

for families. This study reflects this in that analysis showed an increase in the need for liaison between the key worker and other professionals around the times of transition, assessment and diagnosis.

The full report discusses the support offered to families as direct or indirect again the highest levels of direct support were needed by families undergoing assessments or transition. Families accessing the highest levels of indirect support came from a greater age range. The key comments from parents for the success of the support were the availability of the key worker and the time to discuss their individual problems. This needs to be considered in further development of the service as the current key worker had the option to work flexibly and frequently contacted or visited families on an evening or weekend.

The project allowed the families to dictate the type of support and level of support they received thus allowing them to 'design' or be 'at the centre' of their own service delivery (TftS 2002, NCSF 2004, ECM 2005). Families were allowed to have ownership of their support and interestingly did not demand support when they did not need it. This was manageable within the project however if the number of families accessing the service increased the service would need to expand to meet the demand.

In looking at why families were referred to the service it is interesting to note that 96% were to support the family around ASD specific issues reflecting the need for families with children with ASD to have access to a key worker specifically trained in ASD (NAP-C 2003).

The vision for future service delivery for families with children with disabilities is to have one key practitioner acting in a 'lead role' (Lead Professional Good Practice Guidance 2006) in order to

reduce fragmentation and co-ordinate family support thus improving outcomes for children and young people (TftS 2002, NCSF 2004, ECM 2005). This project identified and supports that a key worker for families with disabled children, in this case children with ASD requires a professional who:

*“Has a limited case load which enables the child and family to be supported long term, both emotionally and practically” (DfES 2006).*

This evidence needs to be considered along side DfES guidance however the model used within this project should be considered as a practical and sensible way to both meet the needs of families of children not only with ASD but with other complex disabilities.

## **Evaluation of the Key Worker Service for families with Children Diagnosed with Autism Spectrum Disorders in County Durham**

The post of project worker for the developing of services for families with children diagnosed Autism Spectrum Disorders (ASD) commenced in November 2003. This report is an evaluation of project and the development of a Key Working Service for families with children or undergoing assessment towards a diagnosis of Autism Spectrum Disorder.

### **The initial Aims and Objectives of the Project were:**

To examine and develop the Key Worker role for children diagnosed with Autism Spectrum Disorders (ASD) or undergoing multi-agency assessment building on existing good practice.

To develop guidelines and information to enable parents to have a better understanding of the Key Worker Role.

To provide a named person as first point of contact for parents with children on/or suspected to have an Autism Spectrum Disorder (ASD).

To present families with the information and support they need in a way that is appropriate through involving them in planning and delivery of these services.

To develop ASD specific Family Services Plans (FSP) and promote the use of family held records.

To deliver training to improve professional knowledge and skills so that professionals working with families have the right knowledge and skills to do the job.

Service development and review so that service providers can assess the quality of the intervention and plan for development.

Develop and maintain partnership across agencies.

Produce a report from the project through evaluation of the Key Worker Service, which can be developed and used for families with children who have special needs other than ASD and Communication difficulties.

## **Considerations in planning and development**

### **Autism Spectrum Disorders and the impact of diagnosis on families**

Autism Spectrum Disorder (ASD) is thought to be a neurobiological condition of the brain, which impacts on the individual's development (Prior 1992). The resultant difficulties produce a cluster of features, which provide the diagnostic criteria for autism (Wing & Gould 1979). These clusters of features are referred to as the Triad of Impairment (Wing 1988) which can be identified using diagnostic criteria used by the World Health Organisation 'ICD- 10' (1990) and the American Association 'DSM-1V (1994).

The core features of ASD are impairments in social interaction, delayed, absent or impaired language and communication skills, problems with rigidity of thought and stereotyped behaviours (Jordan & Powell 1995, Richer & Coates 2001). Individuals therefore have difficulties with social relationships, verbal and non-verbal communication, and development of play and imagination and with change in routine (National Autistic Society 2002). ASD is described as a communication disorder (Williams 1996) with individuals experiencing difficulties with all communication including non-verbal communication. Individuals have limited use of gestures and body language. They also have difficulty understanding and interpreting facial expression (Attwood 1998).

There is an inability to interact with and in some individuals a lack of desire to interact with peers. Individuals display a lack of appreciation of social cues and often demonstrate socially

and emotionally inappropriate behaviour (Attwood 1998). Williams (1996) describes this as an impairment of the ability to act socially.

Individuals with ASD are described as having a lack of 'theory of mind' (Baron-Cohen 1995) or an inability to understand that others have their own unique view of the world and have different thoughts and beliefs to themselves (Randall & Parker 1999). They also experience problems in recognising and understanding their own emotions (Williams 1996, Attwood 1998, Lawson 2001).

Individuals often have unusual or restricted interests and can display compulsive, ritualistic or stereotyped behaviours (Schopler 1995).

Current studies have also identified additional sensory 'differences' in individuals with ASD. (Myles et al 2000, Bogdashina 2003). They describe individuals as experiencing sensory agnosia or difficulties interpreting their senses. This is linked to bizarre responses to sensory stimulus (Williams 1996). Lawson (2001) also discusses processing problems or delayed processing in individuals with ASD suggesting that they process pieces of information one at a time (Lawson 2003). This is described as being single channelled or mono-tropic (Lawson 2001) or experiencing mono-processing (Bogdashina 2003). However (Lawson 2001) does not consider herself as 'disordered' or 'impaired' but experiences her Autism as being "dis-abled" in a world which does not understand Autism.

Gaining a full picture of how many families are supporting individuals with ASD is difficult as there is no national register for ASD. The Medical Research Council (2001) reported on

difficulties in ascertaining the numbers of individuals with ASD although their review indicated that ASD occurred more frequently than had been previously identified affecting approximately 60 per 10,000 (1 in 166) of children under eight years old. Within the total population the National Autistic Society (NAS 1996) estimated the prevalence to be 91 per 10,000 in the total population (1 in 100). It was suggested that there is a tendency to over look ASD because there is no central data kept on the incidence of the disorder (Dobson 1996).

Richer & Coates (2001) examined parent's views and understanding of ASD and found that it was the child's social behaviour and relationship to them and others which was most apparent and most devastating to them. The stresses parents experienced related to their child's normality of appearance, vulnerability, communication and behavioural difficulties. ASD was seen as a difficult and demanding condition to live with, with a need for constant supervision placing major restrictions on their lives. They also highlighted the stresses of living with ASD with common themes. These were battling for a diagnosis, battling for services, dealing with their child's behaviour, and other people's lack of understanding of ASD and the subsequent insensitive reactions to them and their child.

## **Key Worker Model**

Examination of the key worker role was made through a comprehensive literature search that highlighted existing good practice and demonstrated which models of support worked best for families. This literature search also highlighted the complexities of Autism Spectrum Disorders (ASD) and the impact of diagnosis upon families. The project worker was also aware through her own previous research of the types of support local families with children diagnosed with ASD valued and found most useful. This assisted in informing the initial development of the role.

Analysis of the findings of a previous study was made and in conjunction with the inclusion co-ordinator and the multi agency ASD steering group the project worker then produced a draft model for key working with families of children with complex communication difficulties and autism spectrum disorders.

## **Key Working**

*“All accounts of those families who had received a ‘true’ key worker service were very positive.” (Mukherjee et al 1999)*

Research identifies families as describing a ‘constant battle’ to achieve the level of support they require (Quine & Phal 1989, Sloper & Turner 1992, Baldwin & Carlisle 1994, Beresford 1995, Chamba et al 1999, Geldard 2004). They also report that families experienced difficulties finding out about all the various agencies, what they did and what services are available to them and information about all the various professionals and their roles. They also experienced problems

getting those professionals to understand their situation and their needs as a family and had problems convincing professionals that they have an in-depth knowledge of their child's needs. Families also report problems with tackling delays and bureaucracy.

Research highlights that many families are involved with numerous professionals from various different agencies (Sloper & Turner 1992, Gordan et al 1990). Families subsequently suffer from the lack of co-ordination between these agencies and have to make multiple contacts some between ten and twenty times in one year (Gordan et al 1990).

Legislation is now stating that families **must** be provided with a Key Worker as a single point of contact to liaise with services and help them to access what they need both for their child and themselves as a family (National Autism Plan for Children NAP-C, National Service Framework for Disabled Children NSF).

Evaluative research on Key Working indicates that parents feel their relationship with professionals was improved as a result of having a Key Worker (Beresford 1995)

### **The Key Worker Role (Mukerjee et al 1999)**

#### ***A key Worker:***

***“A named person whom the parent approaches for advice about any problem related to the disabled child. The Key Worker has responsibility for collaborating with professionals from their own and other services.” (Mukerjee et al 2000)***

Mukerjee (2000) describes an effective Key worker as a person who has regular long-term contact with the family and child. The Key worker provides information about services, benefits and educational settings and advises/supports the family and acts on their behalf. They are also advocates for family and services and co-ordinates services for the family. It is important that contact is two-way and can be initiated by the Key Worker and/or by the family.

*“There needs to be an emphasis on effective communication across all agencies and communication with families (Mukerjee et al 1999).*

### **Key Worker Model (Mukerjee et al 1999)**

The organisational context needs to be multi-agency with a commitment to supporting and developing multi-agency working. There also needs to be ongoing training and supervision of the key worker.

The outer ring of the model is therefore the organisational multi-agency context with a commitment to supporting and developing multi-agency working with the next ring being training & supervision. Training needs to be offered to all agencies or organisations involved in providing services to disabled children and their families. It is also beneficial to have supervision/feedback from the multi-agency organisation.

This encircles the key worker role, which is divided into the six elements of key working.

Families identified these as distinctive compared to the other services they received. The size of these elements can change highlighting the importance of individualistic and responsive role of the key worker.

### **Six key elements of key working;**

1. Pro-active, regular contact
2. A supportive, open relationship
3. A family centred approach
4. Working across agencies
5. Working with families' strengths and ways of coping
6. Working for the family as opposed to working for an agency

### **Child and their family at the centre**

This model of Key working places the child and their family at the centre with the foundations of support ultimately coming from the multi-agency organisation.

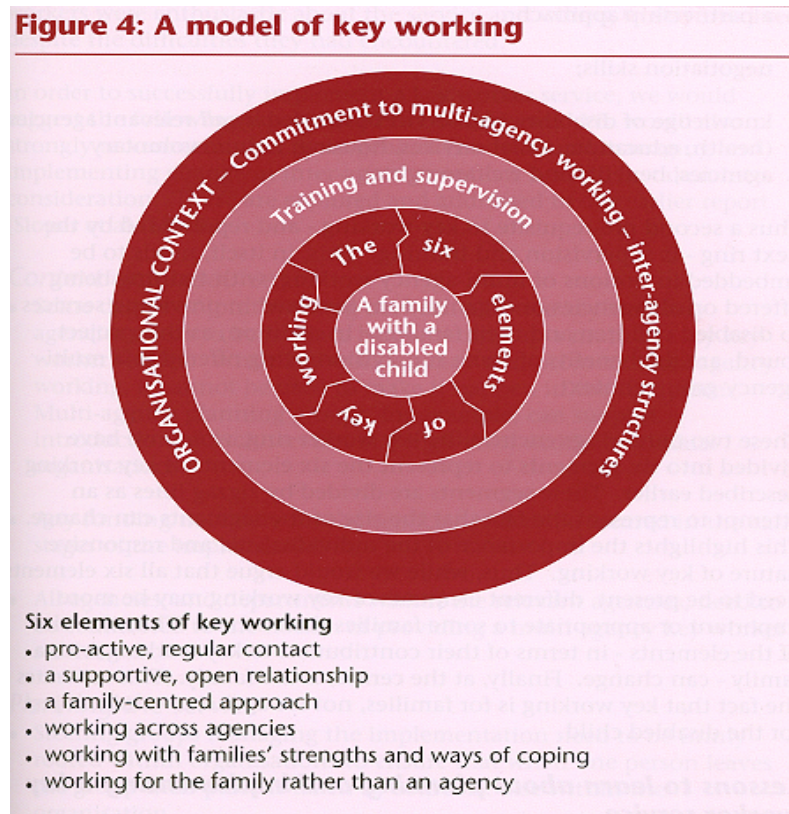
It is important in developing a Key worker model to examine the necessary skills and qualities

Parents identified key workers as needing (Dunst et al 1998). Dunst et al (1998) reported these as being; basic counselling and communication skills; respect for parents' and children's expertise about their own lives; use of a partnership approach; negotiation skills and knowledge of disability and services provided by **all** relevant agencies (Health, Education, Social Service, Housing, Leisure, Voluntary Agencies, Benefits and Welfare Rights). It is also important to note that Key working is for the family not just the disabled child.

## Planning and Implementing a Key Worker Service

The Key Worker needs to be proactive in sustaining contact with families and maintaining liaison with other agencies on their behalf. There also needs to be willingness to stay involved despite any difficulties they may encounter. Research also identifies that it is vital that when a Key Worker is acting as an advocate for a family they need to be independent (Mukerjee et al 1999). Key Workers will also need protected time.

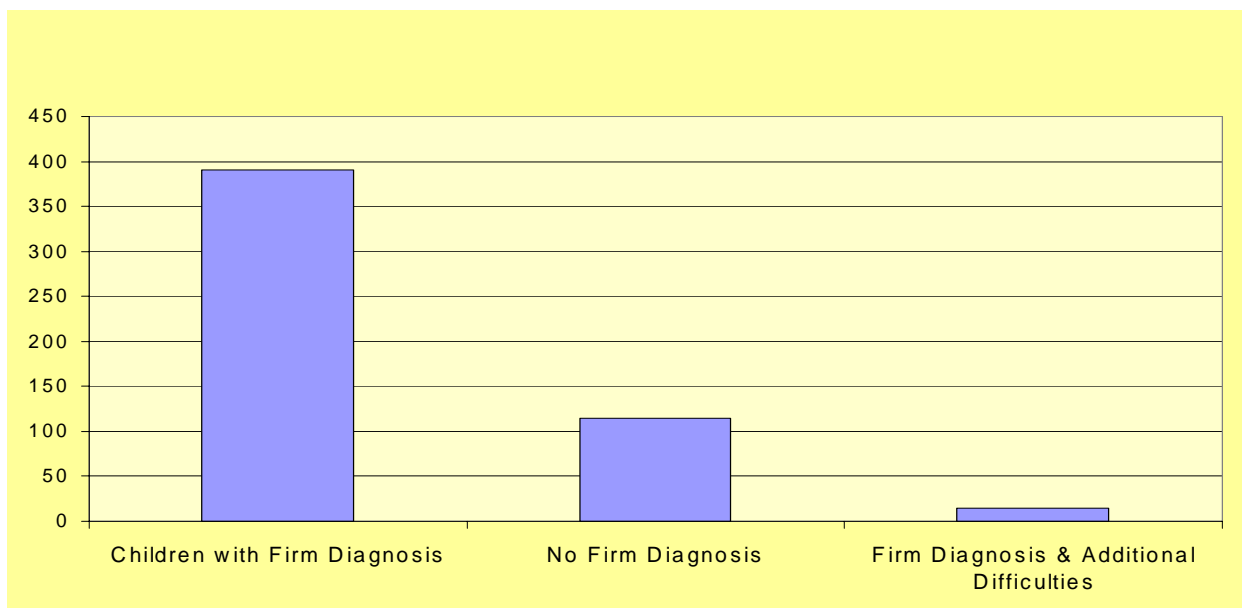
Key Working can promote multi-agency working but interagency working between the three statutory agencies needs to be in place in order to set up a Key Worker Service and all agencies need to be committed to providing a Key Worker service.



## Numbers of individuals with Autism Spectrum Disorders 0-19 years with County Durham

In planning this project it was worthwhile to consider how many individuals with ASD there were living within Durham as this would influence how the project would be focused.

The following data in graph form was compiled in 2002 by Senior Specialist Educational Psychologist Janet Crawford to inform the Multi-disciplinary ASD Group, Durham. Permission was given by this group for this data to be used in appropriate research 11<sup>th</sup> May 2004.



Having considered the number of individuals with ASD within Durham it was decided at the beginning of the project that it should be run as a pilot within a specific area or location otherwise the numbers of families requiring support from the project may exceed the feasible work load for one individual.

Within County Durham there are five Primary Care Trusts (PCT's) and within each is a Child Development Team (CDT) which consists of a multi-agency team involved in the assessment and diagnosis of children. In order to generate a worthwhile yet workable caseload it was agreed through the inclusion co-ordinator that basing the key worker within one CDT should effectively develop the project.

However as the project developed this referral route did not generate the number of families expected so referrals were taken from other agencies and CDT's.

## **Evaluation of the Key Worker Service – Methodology**

In order to produce a report from the project through evaluation of the Key Worker Service, which could be developed and used for families with children who have special needs other than ASD and communication difficulties, three evaluative methods were used. Three methods were used in order to produce more holistic data rather than generating data from only one perspective of the role.

### **Data Collection from Key Workers Caseload**

This was a quantitative evaluation. A framework with which to collect data was designed at the beginning of the project. This was used by the key worker as a method of recording the referral route, the child's age at the point of referral, the type and number of professionals involved at the point of referral, the number of liaison between the key worker and these professionals and all direct and indirect support accessed and provided to families supported within the service. Direct input was categorised as home visits, attending meetings or appointments with the family, visiting schools or services with the family, support group meetings or provision of training which families attended. Indirect support was categorised as contact by telephone, e-mail, letter, facsimile or text (SMS). Indirect support was a two way process initiated either by the key worker or the family.

## **Evaluative Questionnaires**

Towards the end of the project two questionnaires were designed. One was sent to the families who had been supported through the service and the other to the professionals whom the key worker had liaised with. These were completely confidential and guaranteed anonymity for respondents. A stamped addressed envelope was provided for their return.

### **An Evaluative Parental Questionnaire**

The parental questionnaire contained questions to gain both quantitative and qualitative data. They did not ask for any identifying data such as the child's age, diagnosis, type of school attended etc. Families were asked who had referred them to the service, how they had heard about the service and following referral how helpful had they found the service. They were also asked about what type of help, support and information had been provide for them and which of these they had found most useful. The last two questions had asked them to provide comments about other ways they had felt supported by the key worker and if there were any ways they could have been supported to meet their needs which had not been offered. There was also inclusion of a comments section. These last two sections would hopefully generate information which could be used to further develop the service.

## **An Evaluative Professional Questionnaire**

The professional questionnaire focused on obtaining qualitative data through seeking individual professional's opinion of the service delivered by the Key Worker. Professionals were asked if they had directly referred families to the service and what was the reason for referral. They were asked if in their opinion the service had been of benefit to the family and if the support offered had effected communication between the family and other agencies. The questionnaire also investigated their opinion on the impact, if any, on their work as a result of support offered to the family by the key worker and if they had had any feedback from other professionals. The last two sections asked if they would recommend this service and to make any further comments about development or any other aspects of service development they thought would be useful.

## **Findings of analysis of the Key Worker Role from data collection**

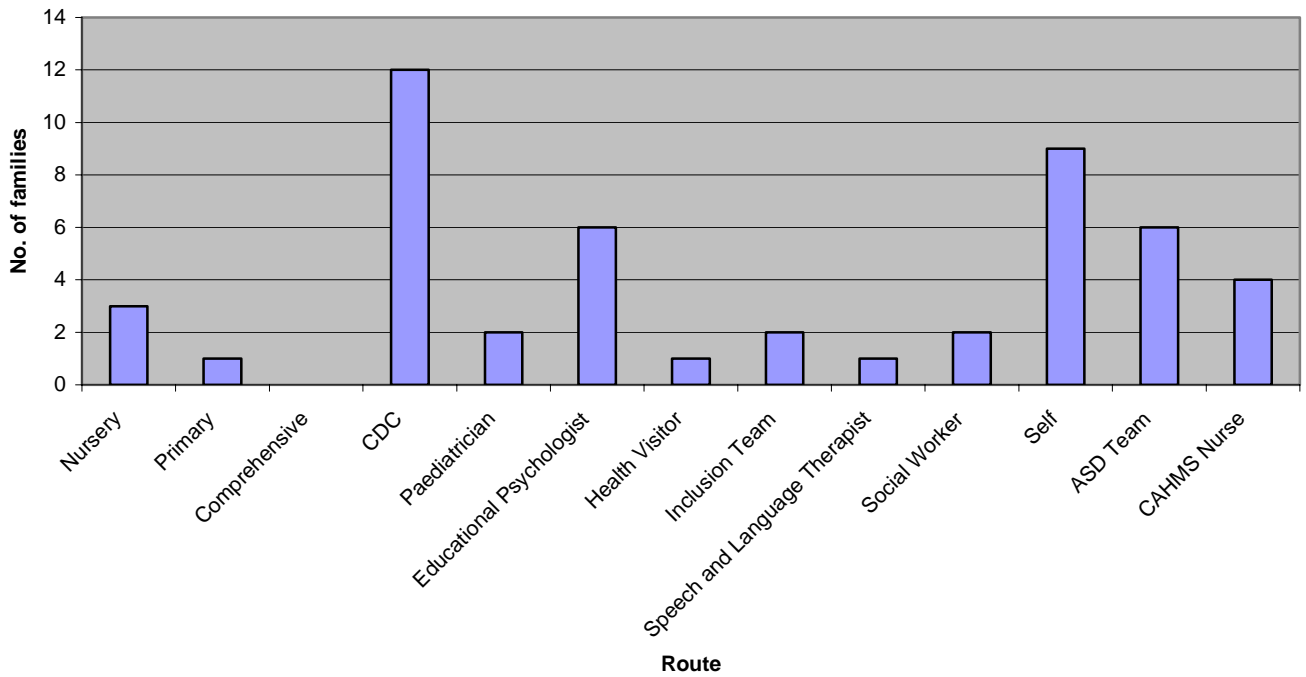
### **Referral routes**

On evaluation greatest number of referrals to the Key Worker Service was made through the Child Development Team 25%. However, 19% of the families supported by the service had self-referred having been informed about the service from various professionals or agencies.

All the self-referrals received were merited and indeed required some of the highest levels of input from the key worker.

12% were referred via the Educational Psychology Service and 12% via the Autism Spectrum Disorder and Communication Difficulties Support and Development Team both services within the Educational Department. These referrals came with permission from the families after these professionals had assessed the family as requiring additional help and support with the child's behaviour or support with annual reviews or writing parental reports for meetings.

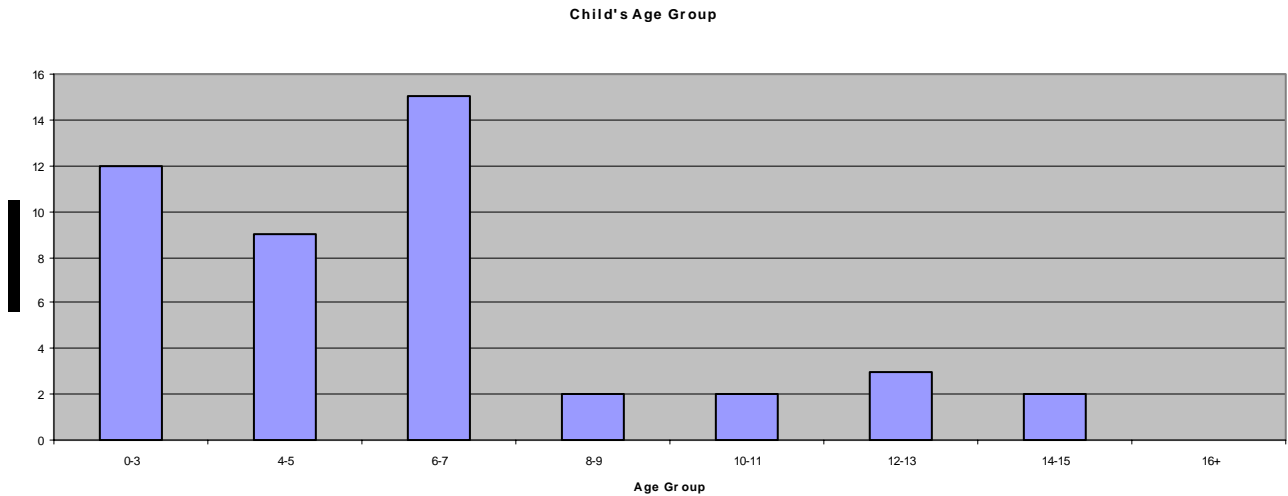
### Referral Routes



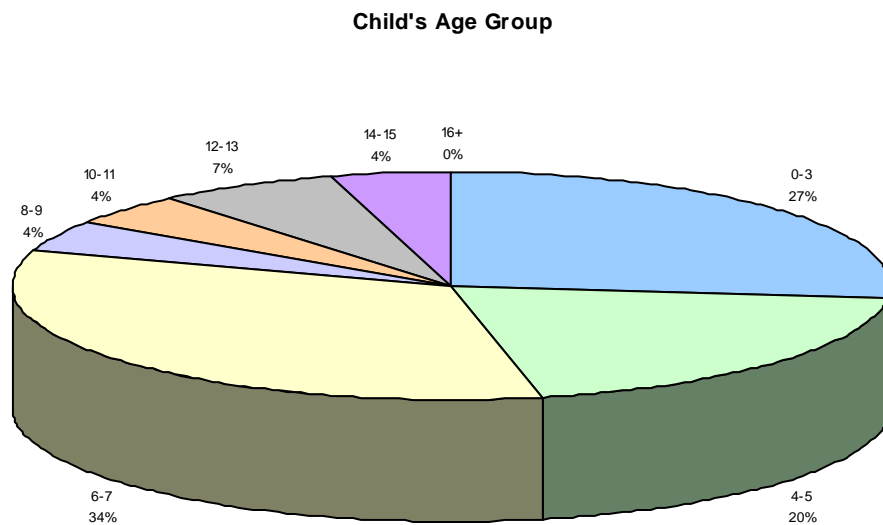
Other referrals to the service were made by the child's school, Paediatrician (not based within a CDT), Health Visitor, member of the Inclusion Team, Sure Start, Speech and Language Therapist, Social Worker and CAHMS Nurse. Again these referrals were made with full consent of the family who were then contacted by the Key Worker.

## Child's Age Group

The age group of the children supported within the service was from 2- 15 years. All had or subsequently received a diagnosis of ASD.



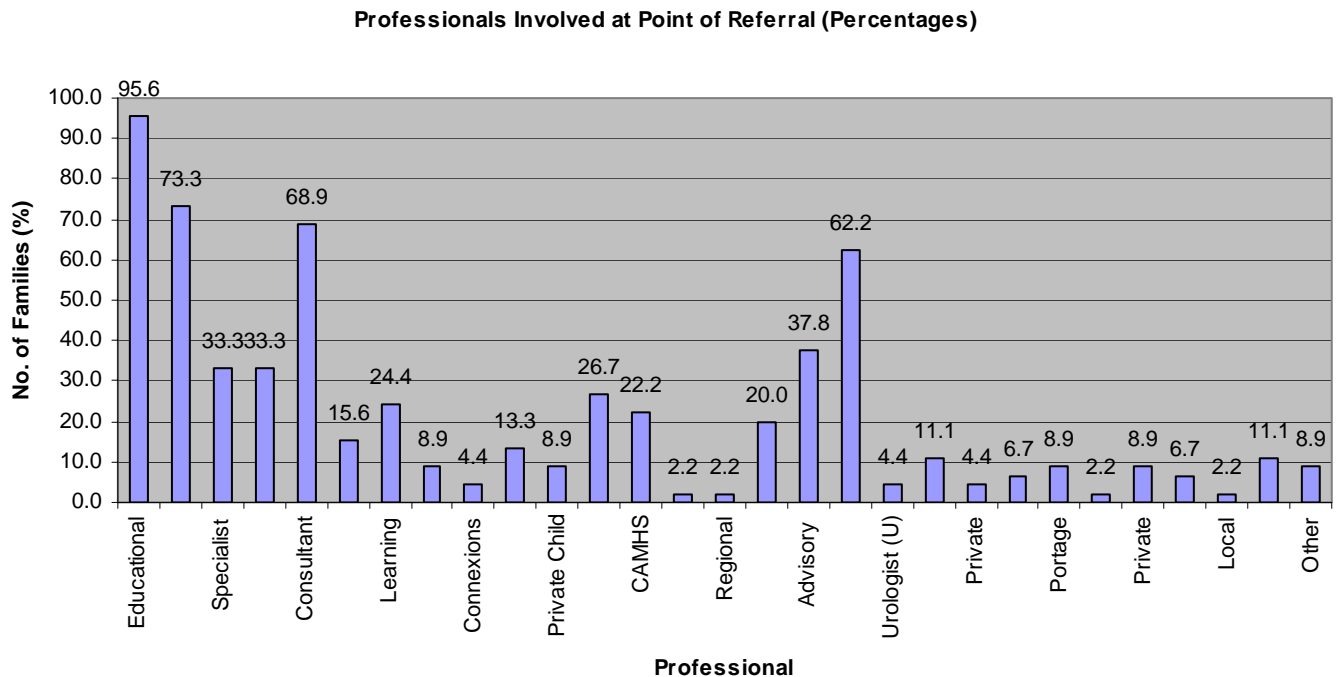
81% of the families supported by the project had children under the age of 7yrs. The families of younger children also required the greatest levels of support from the Key Worker.



## Professionals involved at the point of referral to the Service

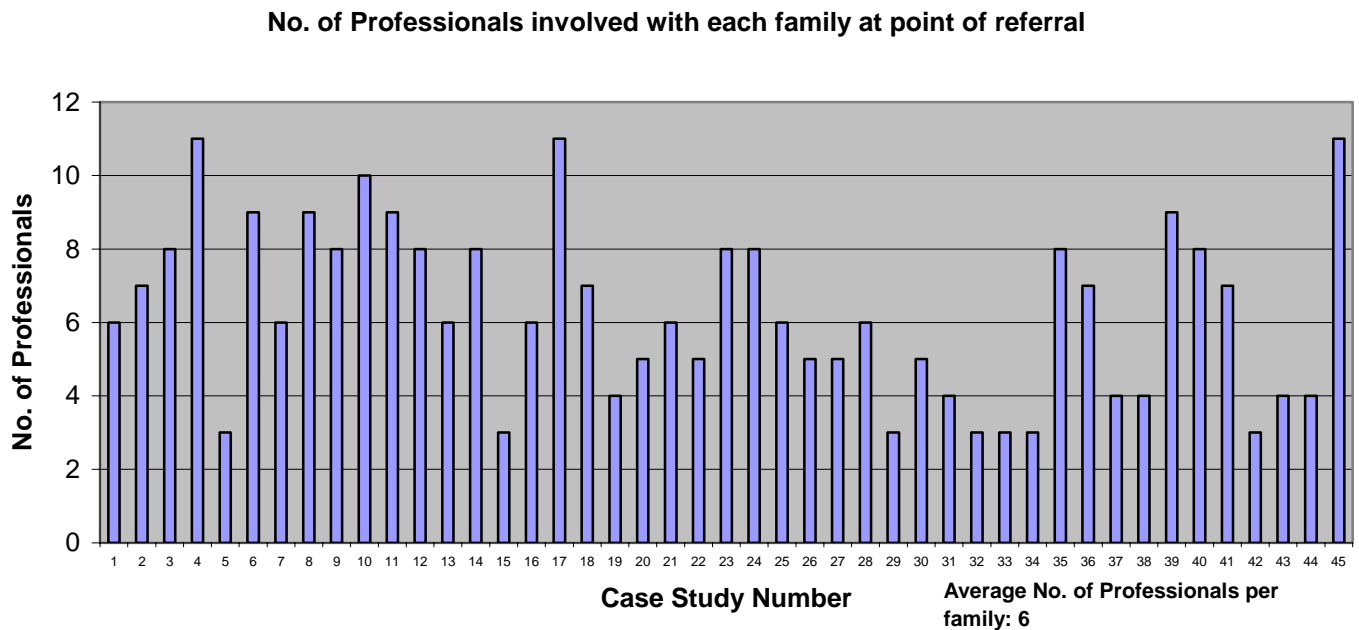
### Discipline of professionals involved with each family at the point of referral

The professionals involved with the greatest numbers of families were Educational Psychologist (95.6%), Speech and Language Therapists (73.3%), Consultant Paediatricians (68.9%) and Mainstream Special Educational Needs Co-ordinators (62.2%). Only a third of the families had a social worker. For the families involved within the study the greatest input from professionals came from Education and Health professionals (81%) possibly as a result of families having children under the age of seven who were undergoing assessment either towards diagnosis or assessment within the Educational system or both.



## Number of professionals involved with each family at the point of referral

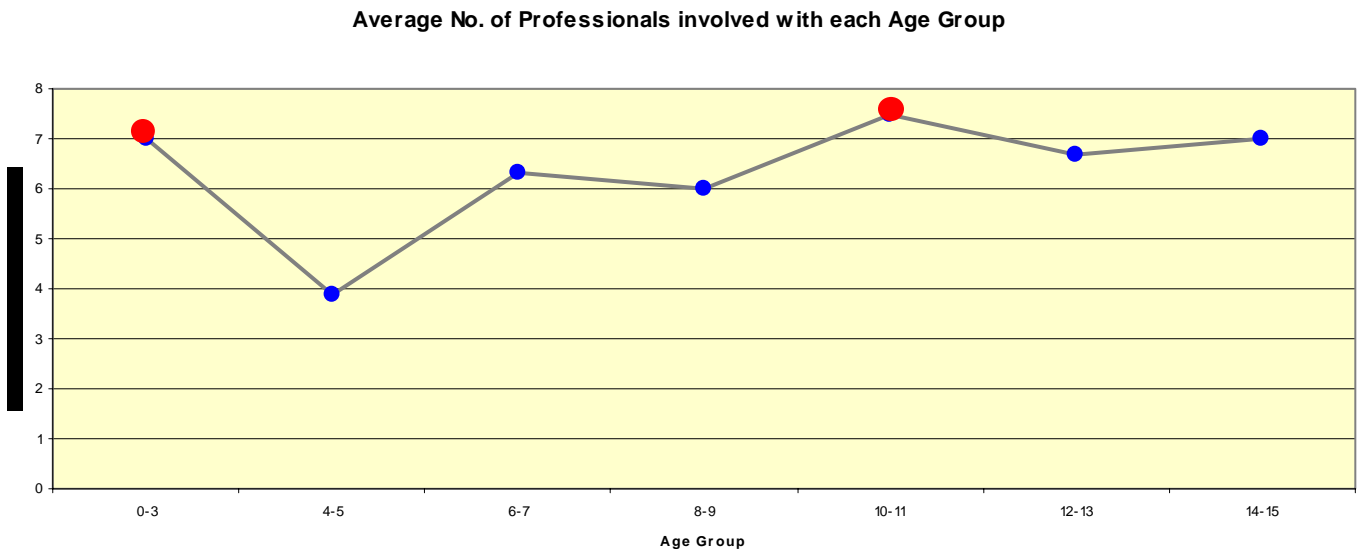
The families within the study had between 3 and 11 professionals involved or in contact with them at the point of their referral to the Key Worker. The average number of professionals involved with each family was 6. This reflects the findings of the National Framework for Children which found that families had on average 6-10 professionals involved with them and their child.



## Average number of professionals involved with each age group

It was interesting to note that the two groups of families that had the highest number of professionals involved with them and their children was those with children aged between 0-3yrs and 10-11yrs.

Those with children aged 0-3yrs were all undergoing assessment either diagnostic or within the educational environment to assess support and educational needs or both. For this reason they had a higher proportion of professionals involved as did the children aged 10-11 who were undergoing transition into secondary education and were therefore in need of higher levels of support or further assessment.

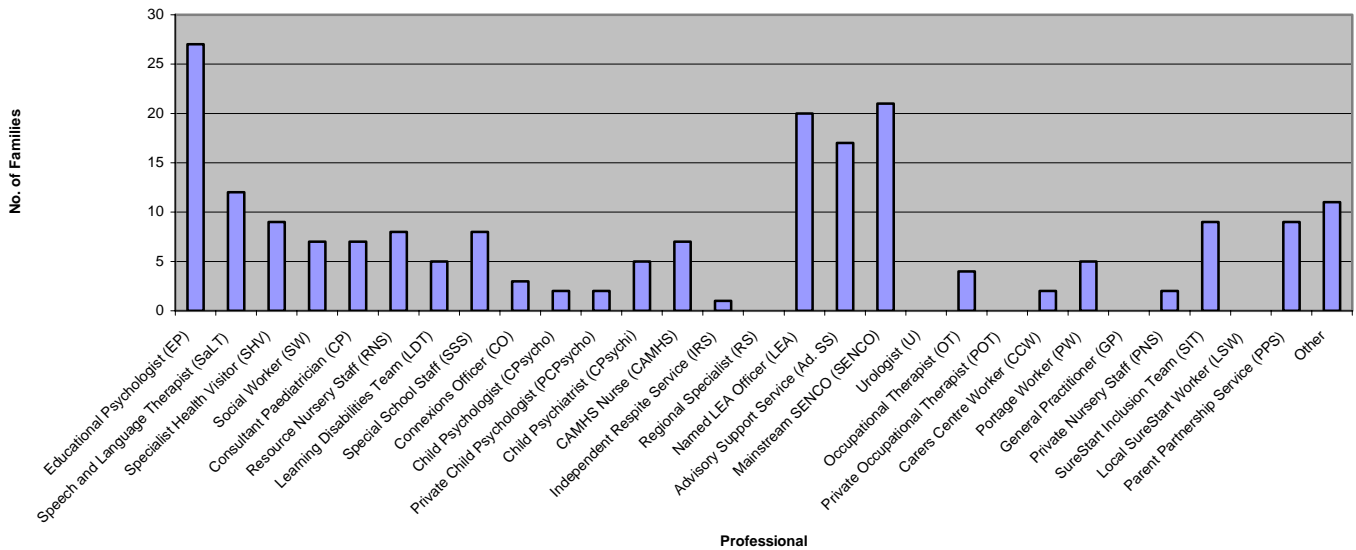


## Liaison with other Professionals or Departments on the families' behalf.

The professionals with which the key worker liaised the most were Educational Psychologists, Mainstream Special Educational Needs Co-ordinators, Named officers for the Local Education Authority and members of the Autism Spectrum Disorder Advisory Support Service.

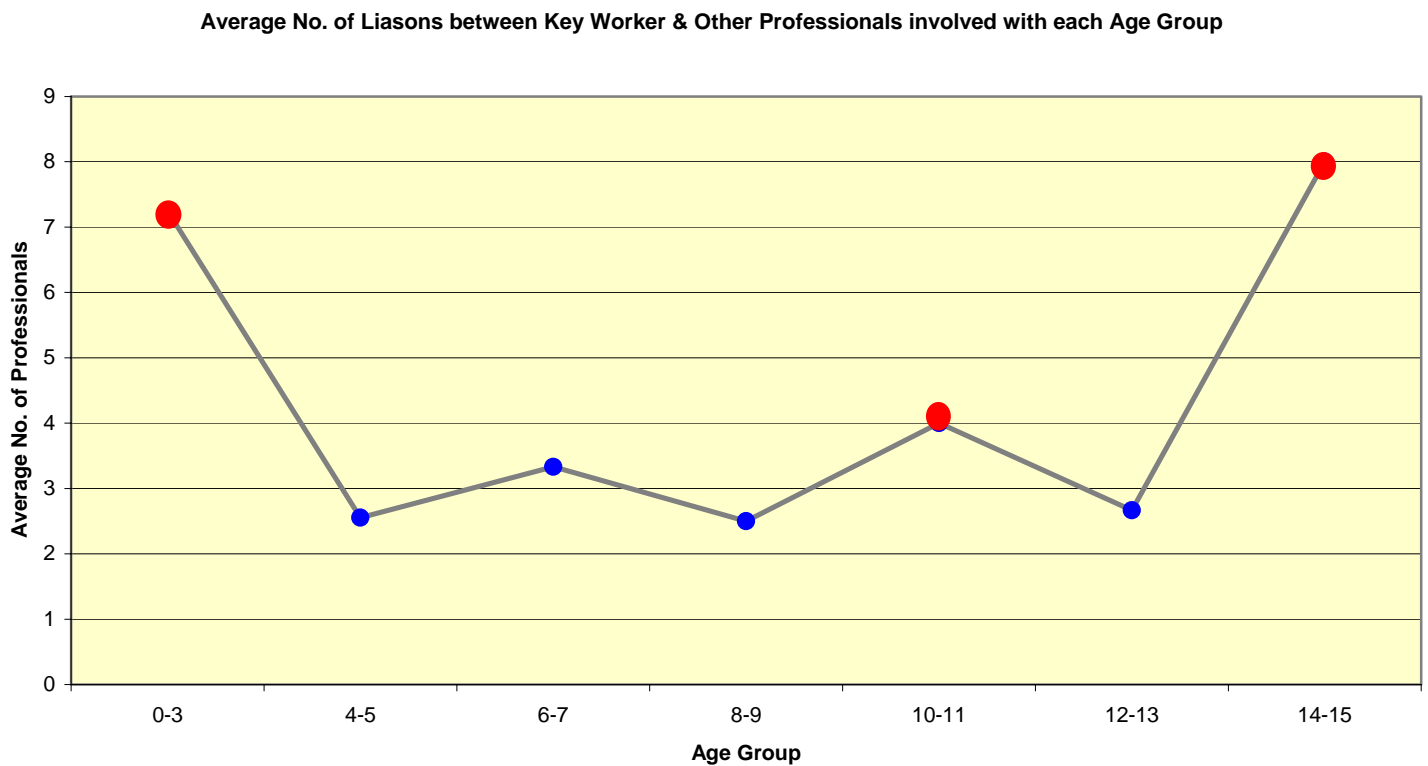
Interestingly these were all from Education Services however it has to be noted that families found the Educational System the most complex and stressful. It was support and information about this service they required the most. Information about Autism Spectrum Disorders and behaviour management was also of a high priority.

Liaison with other Professionals or Departments on Family's Behalf



**Average number of liaisons between the key worker and other professionals involved with each age group.**

Again it is interesting to note that the highest number of liaisons between the Key Worker and other professionals occur at times of diagnosis, assessment and transition where families have the greatest numbers of professional involvement.

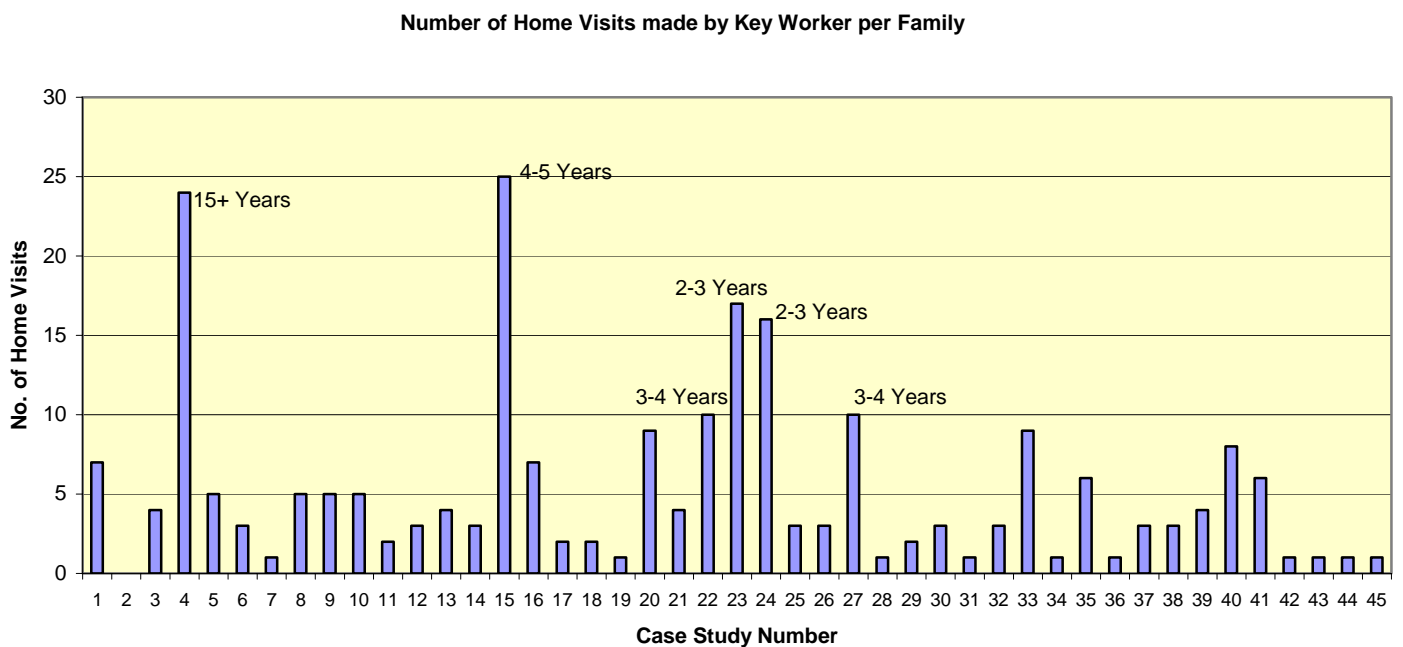


So there was increased input with families of children aged 0-3years as they were undergoing assessment towards diagnosis and for educational support. Increased support for families with children aged 10-11years around the time of transition and transition planning towards secondary education and for families with children aged 14-15years again around transition and transition planning for post 16 years support and placement.

## Number of home visits made by the key worker per family

Home visits were made to all but one family who preferred to have contact via telephone or through the support group meeting, which the Key Worker attended. The highest numbers of visits were made to children less than 5yrs.

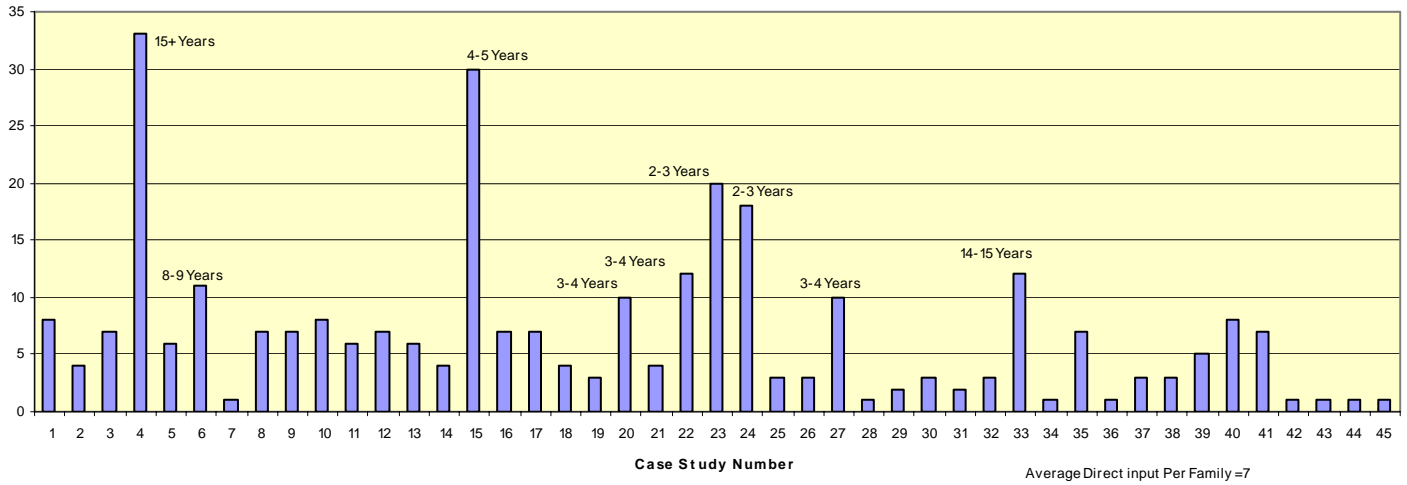
Although one family with a complex young person aged 15+ years required a substantial amount of direct input while their child was going through transition to 16+ educational placement.



## Direct input by the key worker per family

Again the highest level of direct input from the key worker was given to families of younger children but transition periods also required increased support. Categories of direct input from the Key Worker were: home visits, attending any type of meeting/appointment/visiting a school with parents/families, supporting family via support group meetings and training for families.

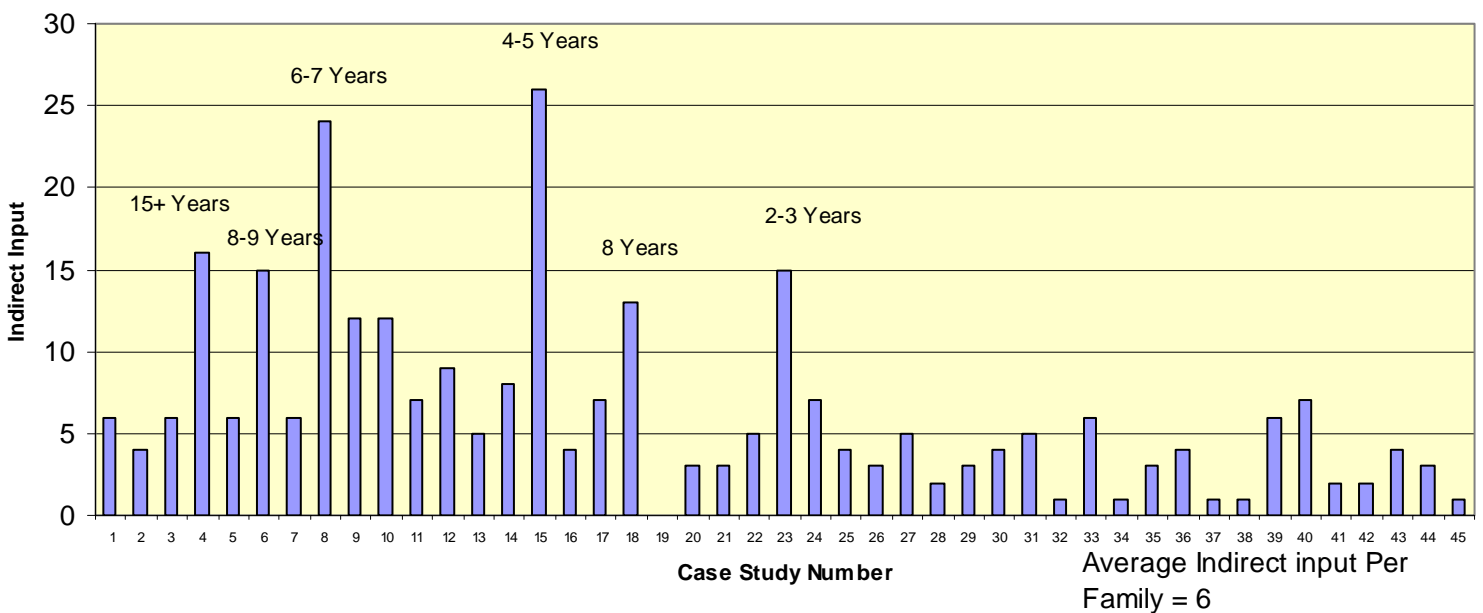
### Direct Input by the Key Worker per Family



### Indirect input by the key worker per family

Indirect input categories were telephone, e-mail, letter, fax or text between the family and the Key worker. It is interesting that the indirect input from the key worker covers a broader age range of children.

### Indirect Input by Key Worker per Family

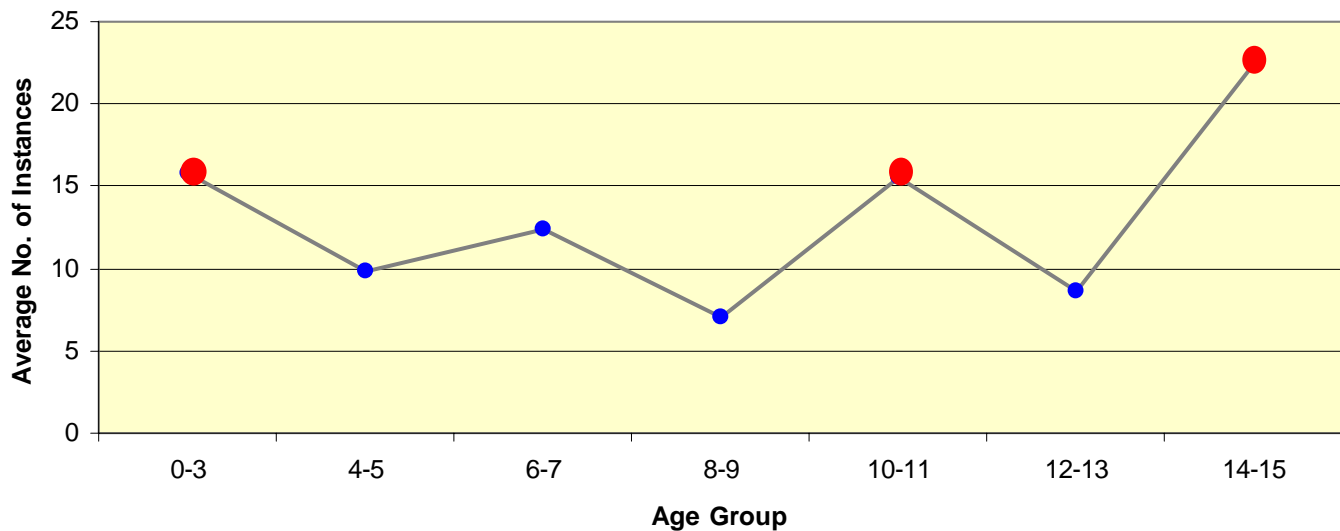


### Average number of incidents of support from the key worker within each age group.

Again the data demonstrates that support from the key worker was required greatest around the early years and times of transition when families' anxieties are at their greatest.

At these points families require increased volumes of information and help to liaise/meet with the professionals involved with them and their child. This is significant as the data shows the number of professionals involved with their families increase at these times.

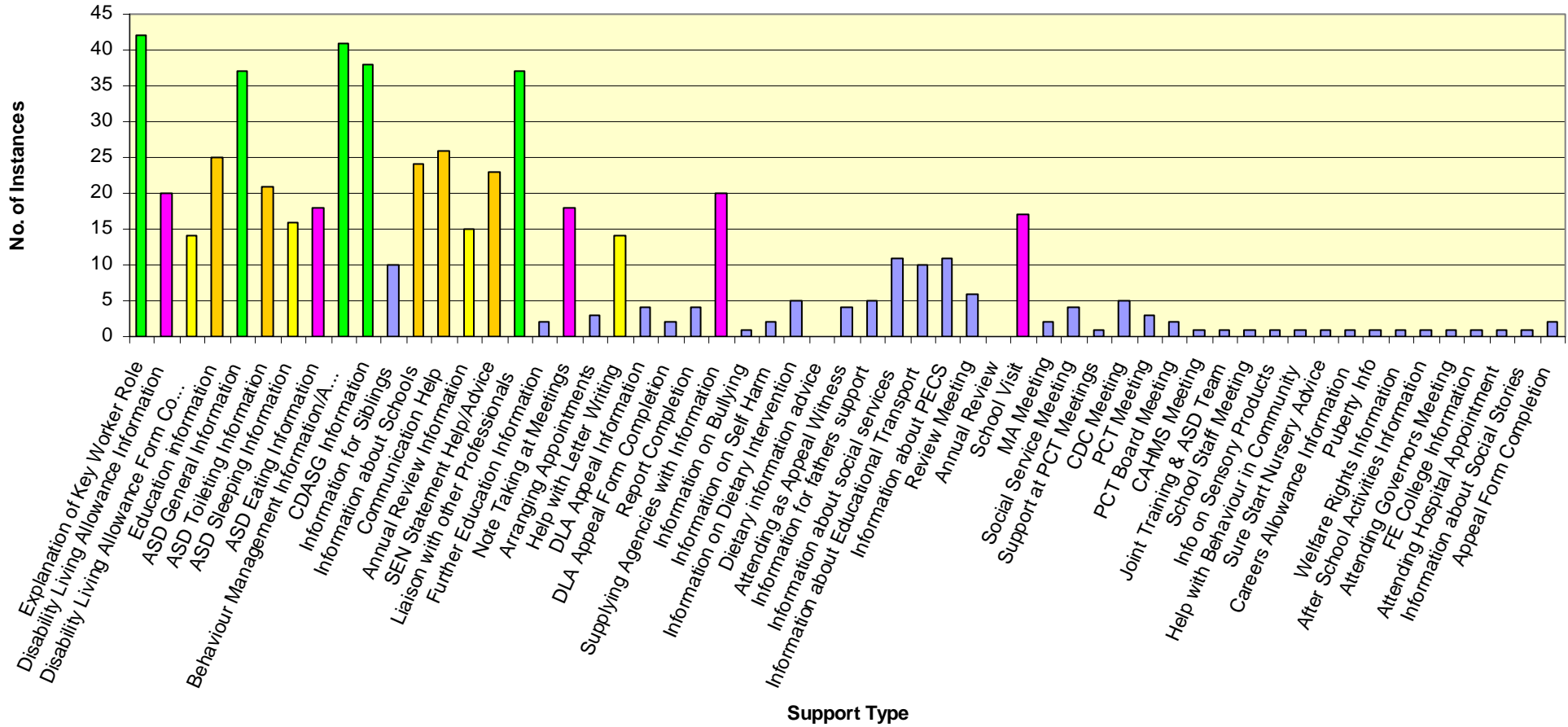
Average No. of Family Support from the Key Worker with each Age Group



### Types of Family support input by the key worker

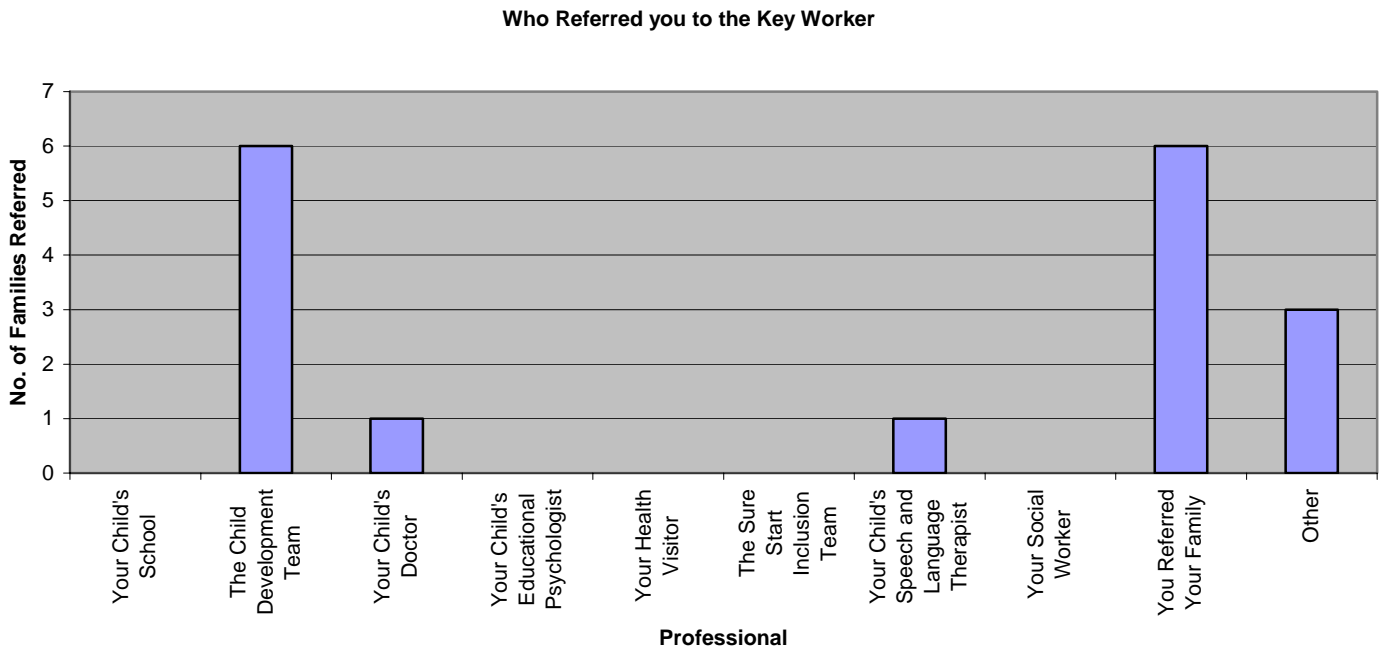
The highest types of support/information provided for families were: Explanation of the key worker role; behaviour management information/advice; information about the local support group; general ASD advice and liaison with other professionals.

### Family Support Input by Key Worker

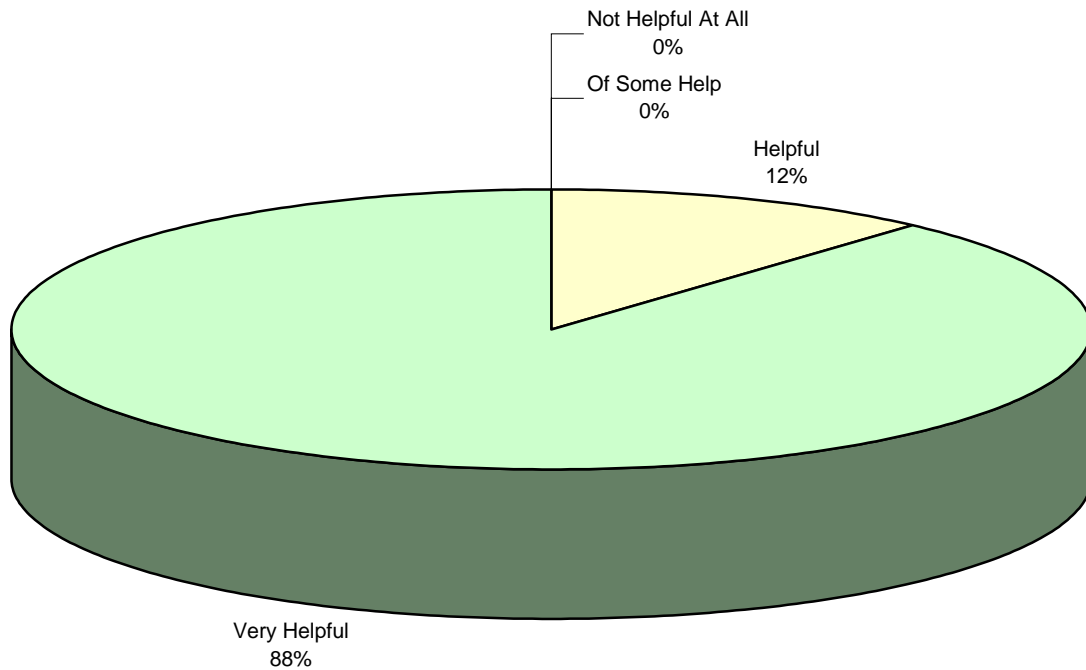


## Analysis of Parental Questionnaire

There was a 45% return rate on the parental questionnaire. The families had been asked to indicate who had referred them to the Key Worker in order to investigate if they understood the referral route to the service. Although none of the families in the returned questionnaires indicated in the tick boxes that the Educational Psychologist (EP) and made the referral to the service some had included the EP and other categorised professionals in the 'other' section. This will have slightly altered the results and was perhaps due to lack of clarity in the design of the questionnaire. However, as with the data analysed from the Key Workers records the highest number of referrals were from the CDT and from self referrals indicating families were clear of the referral route.



### How Helpful Have You Found the Key Worker?



### How helpful did you find the Key Worker?

The responses to this question were very favourable 88% of responders found the service very helpful and the other 12% found the service helpful with none of the responders finding the service of no help or of only some help. As the questionnaires were anonymous the responders would have been free to make any comments confidentially so it was surprising but very encouraging to find no negative comments about the service.

## **What help, support or information has the Key Worker provided for your family?**

There were thirty two categories of help, support and information for responders to indicate they had received from the Key Worker. These categories had been taken from the Key Workers data. All the families who returned questionnaires indicated that they had received information and/or advice about managing their child's challenging behaviour. This was interesting as initially the project framework of aims and objectives it not encompass this need yet this was the area in which all the responding families indicated they needed help, advice and support.

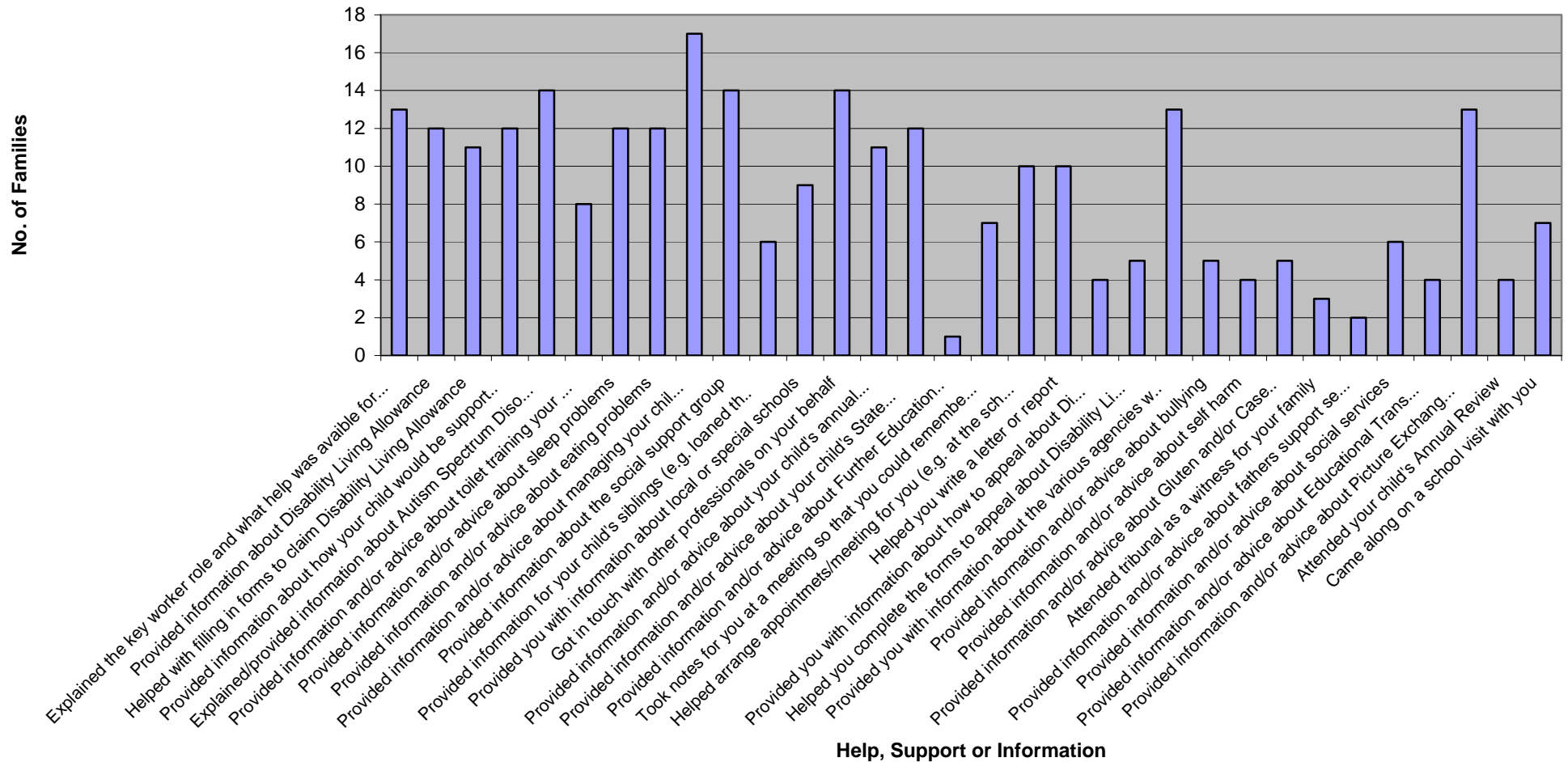
82.4% had needed and received information about Autism Spectrum Disorders. 82.4% had received information about the social support group and 82.4% had needed the Key Worker to liaise with other professionals on their behalf.

76.5% had received information about the Key Worker role and the service. A further 76.5% had received information about various other agencies and 76.5% received advice/help with Picture Exchange Communication System (a visual method of promoting the use of functional communication with individuals with ASD) (Bondy & Frost).

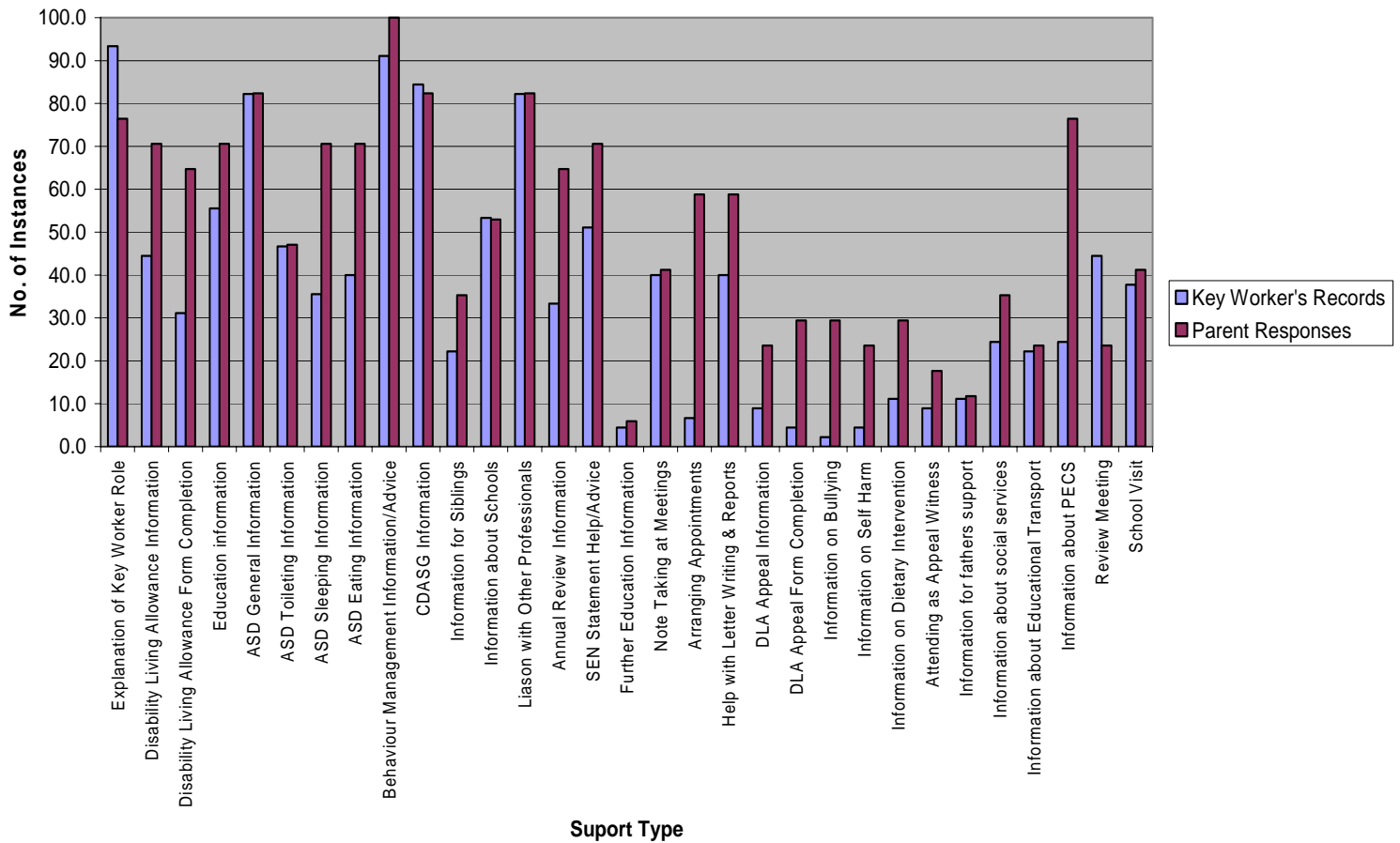
70.6% had received information about Disability Living Allowance (DLA) and 54.7% needed help to complete the DLA forms for their child. Completion of the DLA forms usually took between 2-3 hours to do due to the complexity of the forms. Two of the family had to appeal about DLA decisions both were supported at tribunal by the Key Worker and were successful with their appeals.

Their child's school and education was a concern for many families. This was reflected in the type of support and advice they needed. 70.6% received help, support and information about how their child would be supported in education (e.g. the banding systems used within County Durham, the levels of support their child would receive, the people involved, and the ASD team). 70.6% also needed help and explanations with regard to their child's Statement of Special Educational Needs.

## What Help, Support or Information Has The Key Worker Provided For You and Your Family



## Family Support by Key Worker - Parents Response Compared to Key Worker's Records

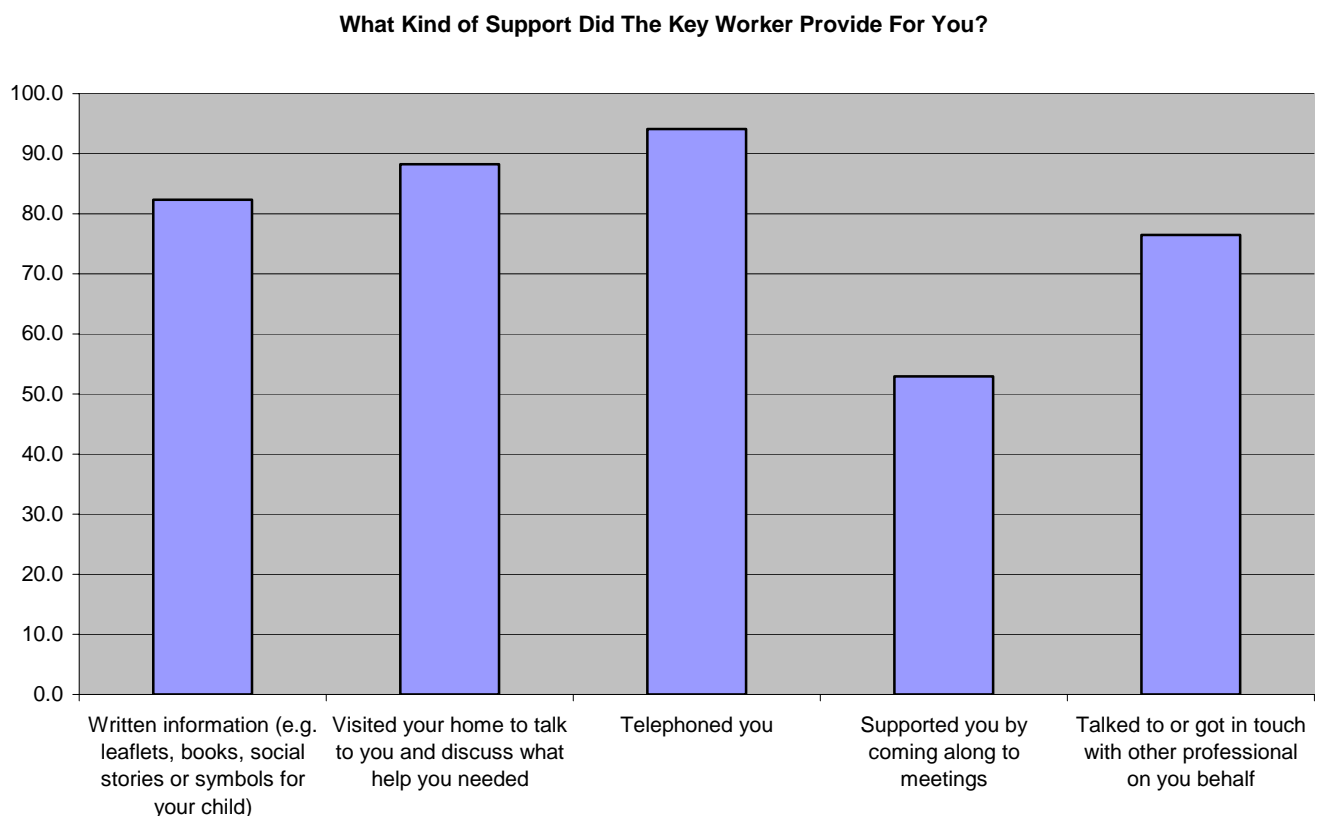


### Support provided to families - Comparative analysis of the Key Workers Data and Parental responses

On comparing the types and amount of help, support and information provided for families by looking at their responses to the questionnaire compared to the data from the Key Workers records there is a strong correlation. It is interesting to note that in all categories except 'Explanation of the Key Worker Role' the families report receiving more help, support and information than recorded by the Key Worker. This could be as a result of not all families who were supported having returned questionnaires or positive bias from those families who did

return questionnaires and considered themselves as having been well supported by the service. However it is still unusual to receive no negative feedback as this type of data collection through questionnaire tends to be returned by respondents with strong views, negative or positive, about the topic being researched (Oppenheim 1992). Overall findings suggest that families were positive about the service.

### Types of Support Families Received from the Key Worker



94% of families reported being supported through telephone conversations and discussions/advice and 88% through the Key Worker visiting their home and spending time talking to them about what help/support they needed or by providing direct advice on specific topics for example challenging behaviour. However 82% felt supported through provision of

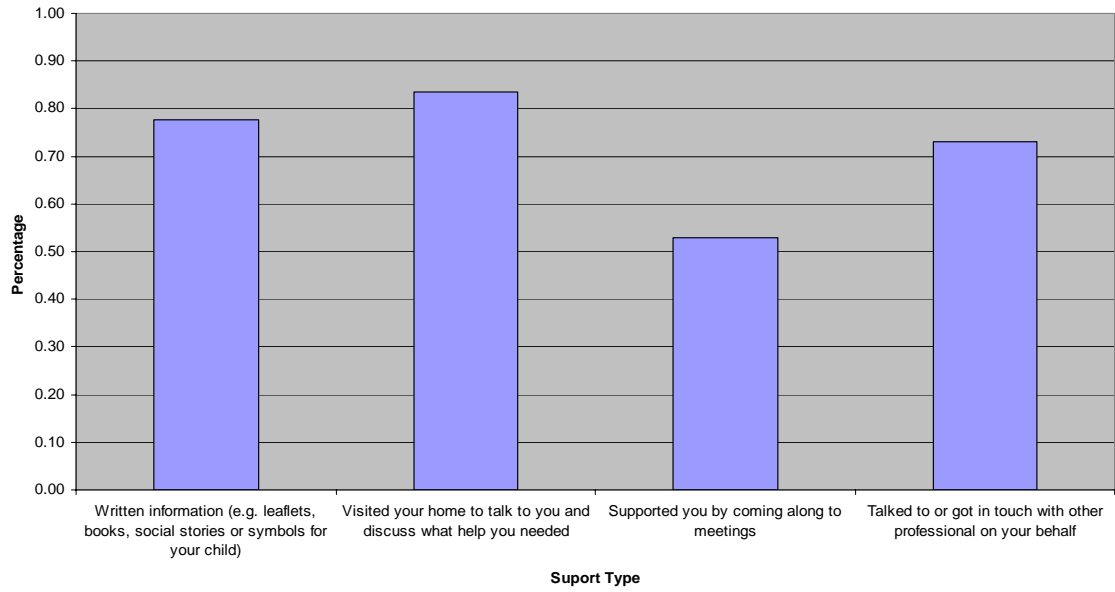
written information although much of the time the Key Worker spent in home visits was spent discussing, explaining and going through written information. It might be sensible therefore to suggest that it was the two methods of support in tandem along with availability of the Key Worker by telephone which provided a package of support rather than one single method of support in isolation.

This is supported by families' response to 'What kind of support from the Key Worker did you find the most helpful?' To analysis this each category was given a score of 1-5 (5 being the most helpful) by the respondent, a total score was then given to each category. This total score was worked out as a percentage of the total possible score each category could have obtained. Home visits (82%), written information (78%) and liaison with other professionals (73%) scored very close with a number of respondents giving a score of '5' for all categories. The fourth category 'support at meetings' scored 52% however this was not a type of support all families had needed.

### **Types of Support Families Found of most benefit**

82% of respondents indicated that the most helpful kind of support was through the Key Worker visiting their home to talk to and discuss what help they needed. This supports previous research which found that families' priorities around the time of diagnosis were provision of information, advice and explanations. With support they most desired being someone to talk to, reassurance and help with interventions for their child.

### What Kind of Support From The Key Worker Did You Find The Most Helpful?



## **Are there any other ways in which your key worker did support you?**

71% of the respondents included comments in this section. Thematic analysis identifies a number of common themes. In descending order of frequency, ‘availability of the key worker’ was found to be the most common theme followed by key worker having ‘an understanding of the problems’ faced by the family and equally ‘spending the time to listen and offer sensible and realistic advice’. Next was the comment of the importance of the key worker having ‘understanding of Autism Spectrum Disorders’ and how helpful and practical this had been especially in helping families manage their child’s behaviour.

*“My Key Worker spent many hours counselling and supporting me through periods of very extreme and difficult behaviour from my child. This provided the vital cushion which saved my sanity”*

### *Parent comment*

The remaining comments interestingly followed a descriptive pattern of how the key worker conducted her role. These were ‘always getting back to families promptly’, providing the ‘time’ for individual families to discuss the issues that they needed to discuss and ‘the flexibility of working hours’. That is the key worker would contact or visit them on an evening or weekend if it was not practicable to do so during the week.

**Are there any other ways in which your key worker could support you?**

41% of respondents made comments in this section a number stating that the support was adequate or that they could not think of any other ways in which they would need support. Other responses:

*“Short of moving in with us – no!”*

*“I can’t think of anything else you could do other than clone yourself so you can be in other places at once!!!”*

*“Can’t think of any specific improvements but long (forever) it may continue I only wish this service ad been in place 12 years ago for my child as it would have made a dramatic difference.”*

*(Parent of a 14yrs old with Autism)*

## **Analysis of Professional Questionnaire**

### **Have you referred any families to the key worker for families diagnosed with Autism Spectrum Disorders?**

75% of the professional who responded stated that they had directly referred a family to the key worker. The reasons given in descending order of frequency where: to help the families understanding of Autism Spectrum Disorders (33%); to help the family with behaviour management (25%); to provide general ASD specific support for the family (19%) and to help with advice and support with toilet training (19%). Other remaining reasons were to support and advise the family regarding communication and their ASD child, provide advice on dietary/eating issues with ASD and help and support with understanding and negotiating the educational system. One family had also been referred as they were described as being 'in crisis'.

### **In your opinion has the support offered by the key worker helped the family?**

All the professional respondents except one answered positively to this question. The professional who responded 'no' made the following comment *"To my knowledge the key worker attempted meetings on several occasions with the family, but with no success, therefore no fault of hers. Perhaps the family not yet ready to meet but may in the future."*

**In your opinion has the support offered by the key worker helped effective communication between the family and other agencies?**

69% of respondents answered positively making the following comments:

*“The key worker is very good at providing a link with other agencies.”*

*“The key worker has always responded promptly to my queries, continued to attend meetings and copied me info.”*

*“Certainly with the area SENCO Team but has also helped with relationships with SaLT.”*

*“It has never been a negative experience to have the key worker involved.”*

*“The key worker has played a central part in meetings with family and other agencies.”*

*“Many agencies and generally the way ‘the system’ works was unknown to families before the key workers involvement.”*

25% were unsure or not able to comment. One respondent felt that this had not really been the focus of the support of the families which they had encountered. Only one respondent given a negative response but did not elaborate through comment so it is difficult to know why they responded negatively.

**Have you noticed any impact on your own work as a result of the support offered y the key worker?**

50% of respondents answered positively to this question. Comments included:

*“Parents became a lot calmer and it was much easier to talk about possible strategies etc.”*

*“This meant that parents are more clued up when they speak to me. It has also meant if strategies are working at home then variations around the strategies can be tried at school etc.”*

*“Through the key worker my own work has developed along with the work of colleagues as we have had information provided by the key worker that was both practical and easy to put into practice.”*

*“My service has less early years (ASD based difficulties) children to support because of the key worker.”*

25% of respondents stated that their own work load had been helped indirectly. Comments included:

*“Not directly so, but it may have reduced the occasions when families might have been in contact with me – but I have no way of knowing this.”*

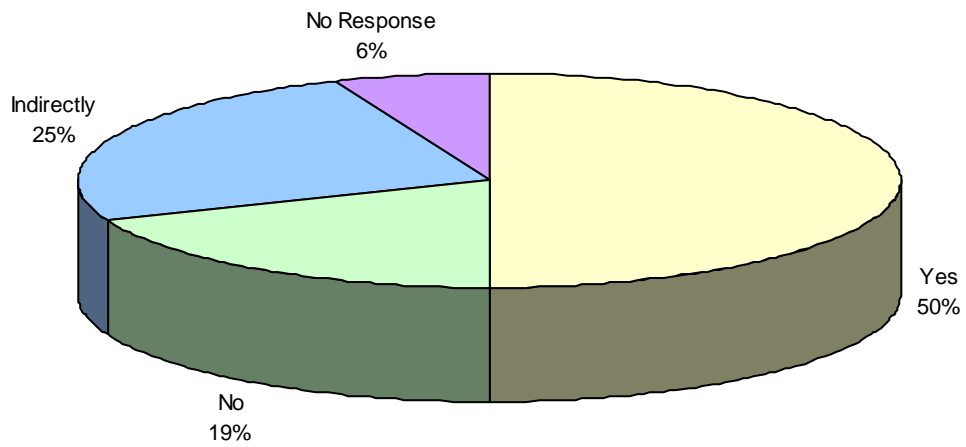
*“The kind of support offered was not directly within my remit, but it was helpful to be able to suggest the involvement of the key worker to families when I knew it was much needed.”*

*“I have found it helpful to talk through the issues with the key worker.”*

*“I feel that I have ‘back up’ someone else to refer to for support.”*

19% responded 'no' and the remaining 6% did not respond to the question.

**Have you noticed any impact on your own work as a result of the support offered by the Key Worker**



## **Have you had any feedback about the service from families or from other professionals?**

Responses were all positive although there were a couple of areas of concern and many referred to parental opinion rather than that of other professionals. . One professional felt that Health Visitors did not fully understand the role. Another was concerned about the scope of the role in terms of geography and also remit.

*“Families think it’s brilliant and nursery saw a change in the family in terms of accepting the diagnosis and being able to put strategies in to help their child.”*

*“Professional comments extremely positive and often relieved at the availability of this support to families.”*

## **Is this a service you would recommend?**

100% of respondents answered ‘yes’. Comments included:

*“It is a very valuable and much needed service for families and professionals alike.”*

*I feel this is a very useful service that I would consider for all children with a diagnosis of complex communication disorder on my caseload.”*

*“Absolutely. It is brilliant in terms of family support and also as a resource in terms of training staff who are working with children with ASD.”*

*“Most definitely – it should be in place for all families within County Durham and beyond.”*

*“The current key worker is an encyclopaedia of information. The service hinges on her knowledge and the commitment, enthusiasm and experience she brings to her role.”*

*“Yes. There is a need for more informal support to families that is knowledgeable and informed and practical that is aimed at the family issues rather than the agendas of the agency.”*

An important comment which needs consideration was:

*“For some families – yes but there is a need to ensure that it compliments other roles.”*

## **Comments**

There was a broad spectrum of comments at the end of the questionnaire. One professional commented that on some occasions they had felt that the key worker had given advice to the family which conflicted with there's. However following discussion it was evident that it was the family's interpretation of information rather than what the key worker had actually said. The same professional also felt that the key worker role had been a very useful and timely resource that had helped many families with children who have a complex communication disorder.

Another professional felt that the key worker role had seemed 'a bit of an enigma' as the role had developed and felt unsure what the role entailed or was linked to in terms of management and direction. They were also uncertain about referral routes.

Other comments included;

*“I have always found the work the key worker does to be valuable and helpful and there would certainly be a gap in provision of this role did not exist.”*

*“I feel parents really view the key worker as an unbiased/non judgemental support, who gets on with the job.”*

*“I would like more opportunity to work with the key worker offering a joint service which worked in school and home at the same time. At the moment its more a happy accident when we are working with the same child.”*

*“From what I have witnessed and experienced of the role provided by the key worker I believe it to be of great importance, giving valuable support and guidance, not just to families but to agencies as well.”*

## Conclusion

Firstly in examining the effectiveness of this service it would be sensible to discuss the aims and objects of the project and whether they had been met. The initial aim of the project was to examine and develop the Key Worker role for children diagnosed with Autism Spectrum Disorders (ASD) or undergoing multi-agency assessment by building on existing good practice. Examination of the key worker role had been made through a comprehensive literature search that highlighted existing good practice and demonstrated which models of support worked best for families (National Autism Plan for Children NAP-C, National Service Framework for Disabled Children NSF). Development of the role had been based on a key worker model (Mukherjee et al 1999). Every Child Matters: Change for Children (Dec 2004) sets out an agenda for integrated services via, among other things, the lead professional role (key worker role). The draft statutory guidance on the Children Act (2004) sections 10 & 11 sets out clear expectations for the implementation of the role. The lead professional is to act as:

*“A single point of contact that children, young people and their families can trust, and who is able to support them in making choices and in navigating through their way through the system.”*

*“Ensure that children and families get appropriate interventions when needed, which are well planned, regularly reviewed and effectively delivered.”*

*“Reduce overlap and inconsistency from other practitioners.”*

*(Lead Professional - Every Child Matters: Change for Children (ECM) 2005)*

The six elements of key working on which the project was developed (Mukherjee et al 1999) does not fully encompass all of the key worker role as described within (ECM) yet interestingly as the ASD Key worker role within this project developed the evaluation indicates that the role actually did meet all the descriptors within ECM.

The publication of the Lead Professional Document (DfES 2006) also describes the role of a Key Worker once more when referring to families of children with complex needs. As the role within this project was developed specifically around the needs of families with or undergoing assessment towards a diagnosis of ASD the description of 'a key worker' role seems to be more accurate rather than 'Lead Professional' which is a role to be provided as necessary for all children (DfES 2006).

In evaluating this project considering a 'single point of contact who families can trust', the natural development of the referral route, the number of self referrals made by families and the various reasons why the key worker was contacted by families, supported by the fact that 100% of those families found the service helpful or very helpful would indicate a 'trust' of the service. The report acknowledges that not all the families supported by the project returned questionnaires however this type of evaluation is usually completed by respondents with strong or specific views (Oppenheim 1992). As no negative views were received it must be considered that the majority, if not all the families, were satisfied with service delivery or had no strong negative views about the service. The project within its limitations also provided a named person as first point of contact for parents with children on/or suspected to have an Autism Spectrum Disorder (ASD).

In order to 'ensure that families got appropriate interventions' the role supported a specific group of families, those with children undergoing assessment or with a diagnosis of ASD. The highest level of support accessed by those families (48%) was ASD specific information/intervention, again supported by the fact 100% found the support helpful or very helpful it would suggest that the support had provided 'appropriate interventions' for those families.

From the comments from professionals it would seem that the role had also had some positive impact on their roles although this could not be measured without further research. It would therefore appear that the initial aim of the project had been met and had interestingly developed not only within the six elements of the key worker model but also following the framework of lead professional described within ECM and expanded upon in the Lead Professional Guidelines (DfES 2006).

A further aim of the project was to develop guidelines and information to enable parents to have a better understanding of the Key Worker Role. Written guidelines from this project will need to be established in conjunction with the Multi-disciplinary ASD Group, Durham and the sub group looking at 'The Lead Professional/Key Worker Role' as part of the remit of the Disability Pathfinder Group, Durham. Initial findings from the key worker project have been used to inform the work around the lead professional development in Durham. It would therefore seem sensible to use the findings of this report to further inform those developments and to develop guidelines to be in place for families with children with all disabilities building upon the good practice to be published in 2006 by the DfES.

The design of the project was also to present families with the information and support they needed in a way that was appropriate through involving them in the planning and delivery of these services. Given that 100% of the families who responded felt that they had received the help they needed and no families reported negatively it would seem that the project was successful in presenting information and support in a way which was both needed and appropriate for those families. It is also arguable that through the evaluation of this project families will therefore be involved in the planning and delivery of services, although each family had not been individually and directly involved in service development.

The project worker was also asked to develop ASD specific Family Services Plans (FSP) and promote the use of family held records. This project aim has not been met in that the key worker has not directly developed FSP although she has been involved within the other groups responsible for the development and use of family held records within Durham. As two pilot studies were already being run it seemed more appropriate for the key worker to be aware and involved with these developments rather than attempt a new pilot within the remit of the role. This was agreed with her line manager. One pilot was using the Early Support Pilot Programme (ESPP) developed parent held records. The other was using an 'in County' developed parent held record called 'The Moving on File'. During the project the key worker was aware of some of the families she supported being in possession of 'The Moving on File' which had been a very positive experience for them. None of the families within this project had experience of the ESPP parent held records so no comment can be made.

Another aim of the project was to deliver training to improve professional knowledge and skills so that professionals working with families have the right knowledge and skills to do the job

(Together from the Start 2002, NAP-C 2003, NSF 2004). This aim had developed along with the project. The key worker had delivered training both jointly with the ASD and Communication Difficulties Support and Development Team and the Sure Start Inclusion Team. A key component of this joint training was the attendance of parents along with professionals. This was something both teams encouraged prior to the project but proved to be important to the project in that the teams supporting the child within the educational setting, the key worker and the family could all provide a consistent approach to working with the child. Although this was not actively researched in the evaluation this may have been a contributing factor to the satisfaction of the families and should be investigated in future evaluation. The key worker has also provided training for Social Service Teams, Learning Disabilities teams, schools and parents.

Service development and review was completed through full evaluation of the project seeking not only the opinions of families but those of professionals and through data collection from the actual project case load. The aim was to publish a comprehensive report of the project which would be accessible to all service providers so that they could 'assess the quality of the intervention and plan for development'. This report will be available to all interested parties both in its current format and as a summary document. The Key Worker also aims to present the findings of the project to generate further feedback in consideration of further development of this service.

Development and maintenance of partnerships across agencies was also an aim of the project. Certainly considering the volume of professionals and agencies involved with the families (3 -11 professionals from all agencies) within the project and the high percentage rate of key worker/professionals liaison on behalf of the families (73%) plus the positive feedback from

those involved, it would seem sensible to conclude that this aim had been met within the limitation of this initial project.

The final aim of the project was the production of a report through evaluation of the Key Worker Service, which could be developed and used for families with children who have special needs other than ASD and Communication Difficulties. This report has been produced in order to meet that aim. In considering whether it can be developed and used for families with children who have other special needs it is necessary to discuss the findings of the evaluation of this project and also to consider these along side National best practice legislation and initiatives such as Every Child Matters (2005), Together From The Start (2002), The Children's National Service Framework (2004) and Removing Barriers to Achievement (2004).

On evaluation the greatest number of referrals to the Key Worker Service was made through the Child Development Team 25%. As this was the formal route that had been set up at the commencement of the project it was sensible to expect the data to reflect this. However, 19% of the families supported by the service had self-referred having been informed about the service from various professionals or agencies. This indicated that this was a service which families did want and felt that they needed. This supports the findings of previous studies and government legislation about the need for families with children with complex disabilities to have Key Worker (Sloper 1999, Mukherjee et al 1999, DfES 2002, DfES 2003, NAP-C 2003, DfES 2004). However, in order to further develop this it will perhaps be necessary to formalise the referral route to the service. Given that the highest level of input provided to families was to those who had self referred an open method of referral for families should be a prime consideration. Open referral provides a proactive way in which to support families giving them choice and control

over service delivery and timing hopefully preventing families from getting to the point of 'crisis' (Every Child Matters 2005, Together From The Start 2002, The Children's National Service Framework 2004 and Removing Barriers to Achievement 2004).

Another consideration was the age of the children of families supported within the project. 81% of the families supported by the project had children under the age of 7yrs. The families of younger children also required the greatest levels of support from the Key Worker. Again this would support the findings of research around the need for early intervention and support for families with children with disabilities (The National Autism Plan for Children's 2003, Together from the Start 2002, Every Child Matters 2003, and The Children's National Service Framework 2004).

The discipline and number of professionals involved with families is also of note. The average number of professionals involved with each family was 6. This reflects the findings of the Children's National Framework (2004) which found that families had on average 6-10 professionals involved with their child and family. For the families involved within the study the greatest input from professionals came from Education and Health professionals which would seem sensible as most of the families (81%) had children under the age of seven who were undergoing assessment either towards diagnosis, or assessment within the Educational system, or both. A third of families had a social worker. The highest levels of professional input were concentrated around families of children aged 0-3yrs and 10-11yrs. These families were undergoing assessment or a period of transition into secondary education. This identified a need for increased support from the key worker around these times.

If the families had had children diagnosed with disabilities other than ASD and complex communication difficulties the number and type of professionals involved may be differently distributed or increased as the NSF would suggest therefore demanding a greater need for a key worker or lead professional (ECM 2005). However, times of assessment and transition should always reflect higher levels of co-ordinated professional support for families (Lead Professional Good Practice Guidance DfES 2005). This is supported by this study as analysis shows an increase in the need for liaison between the key worker and other professionals around times of transition, assessment and diagnosis.

In examining how the key worker service should be developed there is a need to consider how the support needs of families were met within this project. The specific types of support provided for families are highlighted in the analysis section however, for clarity of discussion, these can be referred to as direct or indirect support. Direct being actual one to one contact with the key worker (home visits, attending meetings) and indirect (telephone, written or other contact). The highest level of direct support was given to families of younger children or to families with children undergoing transition. Indirect support was given to families with a much broader age range of children. The types of support provided were advice on behaviour management, local support group information (many families felt socially isolated), general advice about ASD's and liaison with professionals. If the data from all the various support categories are grouped together ASD specific information (48%) was the highest support desired by families. This takes into account behaviour management, toileting, feeding, sleeping issues, communication issues as well as time to talk about and relate ASD to their own child. The next highest was information about Education (21%), liaison with other professionals (16%), attending meetings with the parents (8%) and advice about benefits (6%). However, the key comments from parents for the success

of the support were the availability of the key worker and the time to discuss their individual issues or problems. This needs to be considered in further development of the service as the current key worker had the option to work flexibly and frequently contacted or visited families on an evening or weekend.

Both direct and indirect support from the key worker met the six elements of key working (Mukherjee et al 1999). However, in allowing families' ownership of their support it is interesting to note how the levels naturally fluctuate with family's not demanding support when they do not require it. The project allowed the families to dictate the type of support and level of support they received thus allowing them to 'design' or be 'at the centre' of their own service delivery (TFTS 2002, NSF 2004, ECM 2005). This was manageable within this project although if the project was to continue the number of families accessing the service would have to be considered or the service would need expanding to meet demand.

It is also worth commenting that the key worker was and is a parent of a child with Autism and although this was not a consideration at the onset of the project many parents commented that they felt the key worker had a better understanding of the issues they faced because she was 'a parent' herself. Understandably all key workers can not be lucky enough to have this type of experience but it has proved valuable for this project.

In looking at referrals to the service and any future referral criteria it is interesting to note why families were referred by professionals. The greatest proportions of referrals were to provide support around ASD specific issues (96%). Although some had been referred so that the key worker could support them as they negotiated the educational system and one family had been at

‘crisis’ point. If this project is truly reflective of the needs of families with children with ASD then it would confirm the specific need for the key worker to be fully trained and have a working knowledge of ASD (NAP-C 2003).

If we consider the Draft Lead Professional Good Practice Guidance (2005) the vision for support is that it will be integrated and effectively delivered through one key practitioner acting in a ‘lead role’.

*“The lead professional role is central to the effective frontline delivery of integrated children’s services.”*

*Draft Lead Professional Good Practice Guidance (2005)*

An essential part of this role is to reduce ‘fragmentation and confusion’ of services for families as this can cause delay in children receiving the support they need, and lead to poorer outcomes for children and young people. This reflects the findings of other reports (TFTS 2002, NSF 2004, ECM 2005 and Lead Professional Good Practice Guidance 2006).

This project has been evaluated taking into account the findings of these reports (TFTS 2002, NSF 2004, ECM 2005 and Lead Professional Good Practice Guidance 2006) and previous research. The model on which it was based has been adapted as discussed and from the evaluation has met the required aims and objectives. It has also identified and supports that a Key Worker for families with disabled children, in this case children with ASD requires a professional who:

*“Has a limited case load which enables the child and family to be supported long term, both emotionally and practically’ (DfES 2006).*

In order to further develop this service these findings need to be considered along side DfES (2006) Guidance which states ‘key workers for children with disabilities should have a more ‘in-depth’ and ongoing role for children, young people and families than many lead professionals working with children and young people with less intensive support requirements’. This model would therefore be a practical and sensible way to both meet the needs of families of children not only with ASD but with other complex disabilities and also the requirements of the DfES guidance (TFTS 2002, NSF 2004, ECM 2005 and Lead Professional Good Practice Guidance 2006).

## References

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM-IV)*. Washington, DC, American Psychiatric Association. Cited by Jordan, R. & Powell, S. (1995) *Understanding and Teaching Children with Autism*. Wiley & Sons Ltd, England.

Attwood, T. (1998) *Asperger's Syndrome A Guide for Parents and Professionals*. Jessica Kingsley, London.

Audit Commission (2003) *Services for disabled children – A review of services for disabled children and their families*. Audit Commission, London.

[www.audit-commission.gov.uk](http://www.audit-commission.gov.uk)

Baron-Cohen, S. (1995) *Mindblindness: A Essay on Autism and the Theory of Mind*. MIT press, Cambridge.

Beresford, B. (1995) *Expert Opinions: a national survey of parents caring for a severely disabled child*. Policy Press, Bristol.

Bogdashina, O. (2003) *Sensory Perceptual Issues in Autism and Asperger Syndrome. Different Sensory Experiences Different Perceptual Worlds*. Jessica Kingsley, London.

Chamba, R., Ahmad, W., Hirst, M., Lawton, D. & Beresford, B. (1999) *On the Edge: minority ethnic families caring for a severely disabled child*. Policy press, Bristol.

Contact a Family (2003) *No Time for Us – Relationships between Parents who have a Disabled Child*. Contact a Family, London.

Contact a Family (2003) *We're Listening Summary* <http://www.cafamily.org.uk/reports.html>

Crawford, J. (2002). For ASD Steering Group, Durham.

DfES (2002) *Together from the Start – Practical guidance for professionals working with disabled children (birth to 2) and their families*. DfES, Publications, Nottingham.

[http://www.dfes.gov.uk/sen/documents/Dfes-Together\\_From\\_Start.pdf](http://www.dfes.gov.uk/sen/documents/Dfes-Together_From_Start.pdf)

DfES (2003) *Every Child Matters – Green Paper*. DfES, Publications, Nottingham.

<http://www.dfes.gov.uk/everychildmatters>

DfES (2004) *Removing Barriers to Achievement: The Government's Strategy for SEN*. DfES Publications, Nottingham.

DfES (2005) *Draft Lead Professional Good Practice*. DfES Publications, Nottingham.

DfES (2006) *Lead Professional Good Practice*. DfES Publications, Nottingham.

Geldard, H. (2004) *Support for Parents with Children Diagnosed with Autism Spectrum Disorders. Are We Getting it Right?* Dissertation MA Studies in Education, Northumbria University

Jordan, R. & Powell, S. (1995) *Understanding and Teaching Children with Autism*. Wiley & Sons Ltd, England.

Kohler, F. W. (1999) Examining the Services Received by Young Children with Autism. *Focus on Autism and other Developmental Disabilities*. Volume 14, Number 3, 150-158.

Lawson, W. (2001) *Understanding and Working with the Spectrum of Autism: An Insider's View*. Jessica Kingsley, London.

Lawson, W. (2003) *Build Your Own Life A Self-Help Guide For Individuals With Asperger's Syndrome*. Jessica Kingsley, London.

Mukherjee, S., Beresford, B & Sloper, P. (1999) *Unlocking key working: an analysis and evaluation of key worker services for families with disabled children*. Bristol: Policy Press.

Mukherjee, S., Sloper, P., Beresford, B & Lund, P. (2000) *Developing a Key Worker Service for Families with a Disabled Child*. York: SPRU Publications.

Myles, B. S., Cook, T. K., Miller, N. E., Rinner, L. & Robbins, L. A. (2000) *Asperger Syndrome and Sensory Issues Practical Solutions for Making Sense of the World*. Autism Asperger Publishing Co. Kansas.

National Autism Plan for Children (NAPC) produced by the National Initiative for Autism Screening and Assessment (NIASA) (2003). London: National Autistic Society.

National Autistic Society (1996) *Autism – The Invisible Children*. National Autistic Society, London. National Autistic Society (2002) *Autism in Schools crisis or challenge?* National Autistic Society, London.

Oppenheim, A. N. (1992) *Questionnaire Design, Interviewing and Attitude Management*. Continuum, London.

Prior, M. (1992) Recent advances in the neuro-psychology of autism. *Autism: The Puzzle Are the Pieces Starting to Fit?* National Conference Proceedings. Glen Iris, Victoria. Cited by Lawson, W. (2001) *Understanding and Working With the Spectrum of Autism: An Insider's View*. Jessica Kingsley, London.

Quine, L. & Pahl, J. (1989) *Stress and coping in families caring for a child with severe mental handicap*. Canterbury: Institute of Social and Applied Psychology and Centre for Health Studies, University of Kent.

Randall, P. & Parker, J. (1999) *Supporting the Families of Children with Autism*. Wiley, London.

Richer, J. & Coates, S. (2001) *Autism The Search for Coherence*. Jessica Kingsley, London.

Schopler, E. (1995) *Parents Survival Manual A Guide to Crisis Resolution in Autism and Related Developmental Disorders*. Kluwer Academic / Plenum Publishers, New York.

Sloper, P. & Turner, S. (1992) Service needs of children with severe physical disability. *Child: Care, Health and development*, 18: 259-282.

Together for The Start – Practical guidance for professionals working with disabled children (birth to 2) and their families (2002) DfES 0184/2002.

[http://www.dfes.gov.uk/sen/documents/DfES-Together\\_From\\_Start.pdf](http://www.dfes.gov.uk/sen/documents/DfES-Together_From_Start.pdf)

Westling, D. L. (1997) What Parents of Young Children with Mental Disabilities Want: The Views of One Community. *Focus on Autism and other Developmental Disabilities*. Volume 12, Number 2, 67-78.

Whitaker, P. (2002) *The Journal of Research and Practice: Autism*. Vol 6(4) 411-426. Sage Publications, London.

Williams, D. (1996) *Autism An Inside – Out Approach*. Jessica Kingsley Publishers, London.

Wing, L. (1988) The continuum of autistic characteristics. *Diagnosis and Assessment in Autism*. Plenum Press, New York. Cited by Jordan, R. & Powell, S. (1995) *Understanding and Teaching Children with Autism*. Wiley & Sons Ltd, England.

Wing, L. & Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-29.

World Health Organisation (1990) *Mental Disorders: a Glossary and Guide their Classification in Accordance with the 10<sup>th</sup> Revision of the International Classification of Diseases (ICD-10)*.

World Health Organisation, Geneva. Cited by Jordan, R. & Powell, S. (1995) *Understanding and Teaching Children with Autism*. Wiley & Sons Ltd, England.