

# **The Importance of Early Intervention in Developing Early Coping Strategies for Families of Pre-School Children**

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## **Introduction**

In 2004 a new service was established and developed by the National Blind Children's Society in the UK. Managed by The National Family Support and Information Manager supported by an assistant and a co-ordinator.

The project was set up to support families by offering a comprehensive, holistic service for parents and carers of children with a visual impairment to complement the four key services already provided by the organisation

Education Advocacy  
Custom Eye Books  
ICT & Sensory  
Holidays and Activities.

Working with families of children birth to 25.

The main aim of the project was to help, support & empower parents by offering an approach that ensured that they were not left feeling isolated and without practical help and guidance at and around the time of diagnosis.

One of the advantages of the organisation at its then current stage of development was that it was small and flexible yet offered a national UK service which meant it was able to move into areas of need more easily, therefore making a much greater impact.

It was also helpful in that we didn't have to work with an established hierarchy & bureaucracy, which could have stifled development.

To enable us to move to the next stage we needed to first identify the need.

### **The Need**

In the UK there are approximately 24,000 (Keil 2003) children and young people who are visually impaired. These statistics are those known to Local Education Authorities. There are no statistics available from any agency that show accurate figures as there are many children who are multi disabled and the visual impairment is secondary. The result may be that the visual impairment is not picked up at diagnosis and not recognised as the main issue. The child may have a life threatening condition and in need of other medical interventions that may play a significant part in the first few years. Therefore there are children multi disabled having a significant visual impairment who are not included in these statistics.

For families with children who have a visual impairment, the time of crisis occurs at and around diagnosis. This is when families most need early emotional support, timely and quality up to date information, advice and practical help. Families need to be signposted to other appropriate statutory and voluntary agencies and specialist eye condition groups.

If early intervention for families is not available and adequate at diagnosis this can cause further stress on the family causing disruption, partnership and extended family breakdown, therefore as time passes and no support is available families find they are having to pick up on issues that as a unit they might have been able to manage.

Further evidence outlining the need was well documented:

- 1) RNIB (1996): Taking the Time
- 2) Oxford Brookes University UK & Imperial College London UK (2003) Charter for Families of Children Visually Impaired.

The research related to the day-to-day life and experiences of services provided for families of children with a visual impairment.

Nationally in the UK there was not a one-sector approach to family support and early intervention, although there were many other agencies within the sector their emphasis mainly on adults, with only patchy provision for children and families. National Blind Children therefore in September 2004 decided that there was a need for a service, which would ensure families were not left isolated, and without support.

The research carried out involved discussions and meetings with key practitioners, academics and intellectuals who were involved with families and children at early diagnosis. We met with respected Ophthalmologists, Orthoptists, Optometrists and Family Support Practitioners from major disciplines to include three of the major hospitals in the UK where children were diagnosed with severe visual impairment.

We started to work in collaboration with the Royal National Institute for the Blind, Guide Dogs for the Blind, Action for Blind People, Vision 2020UK, Visual Impairment Scotland and a number of other well respected organisations in the field of Visual impairment

It was vitally important that we consulted with parents and from this there was a clear indication that there was the need for a new service.

### **Aims & Outcomes**

- To offer immediate support and up to date information to families at the time of diagnosis.

**Outcome** - within the first year of the project we had supported over one thousand families. Families have been able to access a 'One-Stop-Shop' holistic package of support at the most crucial time. It is important that at the time of diagnosis, parents are not passed from department to department and therefore creating a sense of frustration. Many parents who contacted us were often quite negative. Their experience being that they had needed to contact many different agencies to get support. Often this had led to a great deal of negativity through being moved from one agency to another and still not receiving appropriate information.

- To build and keep updated a central source of information, to include resources available to parents, carers and professionals.

**Outcome** - we set up a resource base and a comprehensive information service housing material covering many aspects of visual impairment in relation to children and practical information for families. For example this included practical programmes for working with a child with a visual impairment, one hundred and fifty information sheets. Information about education, state benefits, eye conditions, textbooks and other relevant material was provided.

- To establish firm relationships with specialist eye hospitals, Local Education Authorities, Social Services and other agencies encouraging signposting for families of newly diagnosed children and young people to the new service.

**Outcome** - as part of our marketing strategy for the service we mainly focused on specialist eye hospitals and those hospitals in many of the regions throughout the UK resulting in many referrals during the first few months of the project.

- To establish a consortium of practitioners working in the area of family support, to ensure good practice and effective inter-agency working and referral at diagnosis, therefore enabling families to feel less isolated and more positive about the future.

**Outcome** - A consortium of Family Support Practitioners was formed from different disciplines all of them were actively involved in delivering family support. All of them had a national perspective regarding the offering of early intervention strategies and practical help. The group mainly looked at the lack of quality support at diagnosis and the patchy provision throughout the UK. One of the most positive outcomes occurred when we concluded that the best placed professionals to offer information at the point of diagnosis were hospital based Orthoptists We are now at the stage after speaking with several key players to move this forward. The overall outcome being for those with knowledge and experience in the field of family support to offer training to Orthoptists.

- To link families together appropriately and sensitively, by telephone, to help combat feelings of isolation.

**Outcome** - many parents expressed the need to be linked with other families especially in regard to specific eye conditions. This we achieved by accessing our database and linking appropriately. Feedback from parents was positive and many felt it helped by listening to one another, therefore gaining a greater understanding of what they were experiencing

- To produce a national directory of information, contacts and organisations for families of children with a visual impairment.

**Outcome** -within six months we had produced a comprehensive directory of information, contacts, organisations and groups. This was the first directory of its kind and the demand has been overwhelming from parents and also professionals working with children and families. Over one thousand three hundred directories have been requested and distributed to families and professionals

- To bring families together at group meetings and family weekends, offering families the opportunity to share experiences and for children to meet others with similar needs.

**Outcome** - We opened a centre for families to meet one another and the opportunity for some parents to receive more in depth intervention. We also encouraged families having children with specific eye conditions for example, (Glaucoma and Retinoblastoma) to meet to share concerns and experiences. Within the year we expanded the centre to hold Information communication technology equipment, specialist toys low vision aids, and a multi sensory room. The organisation already had in place other key professionals, which enabled us to offer more specialist help in the area of Information technology, education support and early practical support for families of multi-disabled children.

- To raise the awareness within the community of families from ethnic minority backgrounds encouraging and enabling minority groups, to participate in our services, share experiences and meet other families. Often due to culture, managing disability can be difficult and with the help of an interpreter, support could be carried out in a sensitive way.

**Outcome** – although in the early months of the project we had the services of an interpreter and contact was made with a few individual families, cultural barriers prevented development of group meetings. Individual families have visited the centre preferring individual help rather than participating in-group meetings.

- To offer practical help and information to families and young people through the delivery of workshops and information days.

**Outcome** – a number of workshops were rolled out during the first year for young people aged fourteen to nineteen with recent sight loss, parents were encouraged to join in the sessions.

- To create a database, to provide statistical information and a method of effectively linking families.

**Outcome- this** enabled us to carry out a national search by region, age of the child and eye condition. Therefore enabling us to link families with other families with children with similar eye conditions, something which we have been able to achieve on numerous occasions.

## **Challenges**

As with all new projects time management is an extremely important area in order to address all the challenges faced.

Specifically challenges faced were:

- Effectively dealing with the volume of enquiries and interventions for the new service whilst meeting individual need. Complications here included: communication and difficulties with literacy, national language difficulties and meeting the needs of different cultures; e.g. people seeking support from other countries living in the UK.
- Keeping up to date with information in the area of legislation, state benefits and current trends.
- Developing credibility in the world of visual impairment with this new service.
- Prioritising the intervention when the point of contact is via the telephone and the difficulties in meeting complicated areas of need, for example having the ability to pick up on non-verbal cues when using this method of communication.
- Marketing and raising the profile of the new service.
- Creating a database and referral system to other key services already in existence within the organisation.

## **Conclusion**

Becoming a parent of a child with a visual impairment can happen to anyone anywhere in world and it is my opinion that a high level of interpersonal skills are needed by professionals in order to deal appropriately with parents whose children have been diagnosed as having a visual impairment. The effectiveness of interventions are dependant on developing sound working relationships with parents. Three essential functions of professionals in working with parents are considered to be; helping parents come to terms with the visual impairment; providing information and the services available; and, linking parents with others in similar situations.

Whilst it has been an extremely positive eighteen months with excellent feedback from many families and professionals, still much remains to be done.

Many families of pre-school visually impaired children have been supported since the introduction of the Family Support & Information service, returning to us on numerous occasions during the early months of their child's diagnosis with new

issues and concerns. The model of holistic support provided has made a tremendous difference to the way in which these families have coped with their child's disability.

For everyone that has been involved in the project from its inception the work has been hard and long but has been very rewarding knowing that we have been instrumental in improving the lives of children with visual impairment and their parents.

### **References:**

- 1) Keil, S: Survey of Education Provision for Blind & Partially Sighted Children in England Scotland & Wales (2003). British Journal of Visual Impairment. Vol.21, Pages 93-97, (Sep 2003)
- 2) Bolton, M, Clegg, S, McDonald, Fielder, A: Oxford Brookes University; Charter for Families of Children Visually Impaired (2003)