

It is such a big weight off my shoulders to know that I can leave him at the playgroup and he is receiving the excellent care and attention that he needs.

Parent from Birmingham

contact a family

for families with disabled children

Messages from parents of children of rare disorders to staff working in Early Years settings

Rare Matters

Introduction

This information sheet is for staff working in all mainstream early years settings. Its aim is to explain to you what rare disorders are and to pass on to you the messages from a survey of parents about the importance of including their children in mainstream services.

By including such children in your service, you can transform the lives of disabled children and their parents. As one parent said *"The play centre is really important for my child as she gets to interact with other children her own age without discrimination."*

What is a rare condition?

A rare condition is one which affects five or fewer people in every 10,000. Individually they are rare but collectively they affect 5-8% of the European population.



On these figures it is likely that 3,700 children in Birmingham have a rare condition.

There are over 5,000 known rare disorders, a statistic which is continually growing as medical science advances. They affect both children and adults and can occur at any time of life. Many disorders are chronic, progressive and disabling. Some are life threatening.

Findings from the survey

51 parents of children with rare conditions gave their views to Contact a Family West Midlands about having a child with a rare condition.

They told us that they feel devastated when they are told that a child in the family has a disability. When the disorder is a very rare condition parents face added problems. These include:

- difficulties in obtaining a diagnosis
- not being given any information about the condition
- feeling very isolated
- anxiety about the child's future
- concern for the child's siblings
- variation of advice and treatment around the country

Parents can feel very bruised by some of the early responses to their baby.

At a Contact a Family workshop they shared some of the responses they had had from professionals, such as:

"I was pushed to have a termination – and told there was no hope for the future."

"A worker told me that most children with that condition die young."

"I was given the name of a syndrome on a torn piece of paper and told to look on the internet but not to believe everything I am told."

“The genetics report was full of terminology and very negative, no information about a positive quality of life.”

In addition, many people have grown up to adulthood living with such a rare disorder that they have never met another person with the same condition. One parent who said *“I was told that there was no other child with the same condition”* later met one quite by chance.

To add to their difficulties parents commonly have difficulties in accessing mainstream early years services. Many parents told us of negative experiences they had had trying to access suitable provision but encouragingly, others had been welcomed into mainstream services. The comments below from parents reflect their positive feelings and wishes to increase the opportunities available for their children with rare disorders in early years’ provision.

All the quotations listed are from parents of children who have a rare disorder who were involved in the project.

What parents said

1. Inclusion

“It can be a very isolating experience time for a parent and sometimes they need to be encouraged to join into the community with their ‘special’ child.”

“For a child with ‘complex’ needs as my son has, there is nowhere you really belong.”

One of the strongest messages from parents was about inclusion. Children with rare conditions are ‘children’ first and need the same opportunities as other children for growth and development. Early Years services can do much to welcome parents and meet the needs of children with rare disorders alongside all children. Activities can be designed to promote equality of opportunity and to show positive images of all children.

By including all children in mainstream settings in the early years of their life, you will build parents’ and children’s confidence and that will assist their inclusion in future services.

Parents said what would help:

“I understand that everyone is afraid of the unknown. However children with rare conditions and their families have feelings to and deserve and are entitled to the individual care and attention to allow them to develop in a safe, happy and stimulating environment, along with other non disabled children. Everyone should have equal opportunities to fulfil their full potential no matter what additional support they may need.”

“Children need to interact with other local children to ensure that they are part of their local community. Children with rare disorders feel isolated in many, many ways. You can help by positively encouraging children to attend your activities. Be pro-active and seek out these families – don’t rely on them coming to you.

“The play centre is really important for my child as she gets to interact with other children her own age without discrimination. The staff are excellent, as is the centre, however more funding is needed to continue to provide an excellent service.”

“Not once have I been made to feel that daughter’s disorder is anything to be ‘oohed’ and ‘ahhhed’ at by the staff. This has made me very happy indeed.”

2. Information for parents and workers

“It really was not easy to find somewhere or someone who knew anything about a rare disorder or to have the time to give extra on a one-to-one basis in a busy playgroup.”

Parents said that they find it difficult to access information on Early Years provision. It would help if services which welcome disabled children were publicised widely to all communities. Additional efforts may be needed to reach families of children with rare disorders and to help them feel they are welcome.

Early Years providers can also do much to help parents to access other sources of information. This will also help services providers become more knowledgeable about what exists for parents of disabled children. Building up a library of information and resources available would be empowering for parents and staff. Share this amongst all the staff involved in the child’s care.

It is important to be honest with parents. They prefer professionals to say if they don’t know and

are willing to find out the information the parents require.

“Many services are available but many people do not know about them. It depends heavily on the parents’ interest and determination, which sometimes is exhausting for parents who are already isolated in a certain way by having a child with a rare disorder.”

“Information, information, information. Need I say more? Please read up on any available information.”

“Assess each child and help them to develop individually. Some children, such as mine who has a rare condition, have hidden problems.”

It makes a huge difference to the families when workers were willing to learn about children with rare conditions.

“The local nursery was very supportive and open to learn about my son’s condition.”

“The main positive was the pre-school playgroup wanting to learn and understand about my son’s condition and at all times checking and re-assuring themselves that what they are doing with him is correct. It is such a big weight off my shoulders to know that I can leave him at playgroup and he is receiving excellent care and attention that he needs and requires.”

3. A welcoming and accessible environment

“Don’t be put off by a rare disorder label – these children will enrich your service and they will be enriched by contact with mainstream services.”

Make sure your services are accessible to parents of children with rare conditions. This may mean adapting the physical environment to ensure that it is accessible for all children. Operate a flexible programme of activities, and have equipment and resources that all children can use.

“The only playgroup in our area does not take toddlers in nappies, which can cause issues for children with special needs.”

“Disabled children may need additional attention and support than children without disabilities. However the benefit of this provision and social interaction to the child and experience of job satisfaction for the childcare worker, cannot be measured.”

By including all children, staff will be more knowledgeable and will be a more experienced environment for all involved.

4. Building trust and partnerships with parents

“Please don’t ignore parents’ advice because we know our children’s needs. Please listen to what parents tell you about their children.”

Families of disabled children are in contact with many professionals, especially when the condition is a rare disorder. Develop good communication with other early years services. Share information and examples of good practice. Learn from each other’s experiences. Disability training, which includes issues around rare disorders, should be offered to all staff within early years settings.

Consult with parents of children with rare disorders. Their views are vital to the success of your service, along with any future developments you have planned.

Partnership with parents is the way forward for positive working. Make time to listen to parents. Develop and promote effective communication between yourself and parents.

Partnership should include the children using your services – children’s opinions count too!

“Make sure you feel able and confident in dealing with the child’s needs. Find out as much as possible about the condition. Ask for specialist support and training.”

“Always be honest about what you can and can’t provide. Use positive images of disability within the setting. Remember the emotional needs of the parents as well.”

“Be aware of what parents are going through and listen to them, as any negativity from you as workers can be devastating to both the parents and children.”

“Always be aware and educated about children with rare disorders. Please listen to parents because they do know their children inside out and are greatly educated about what is needed for their children’s safety, hygiene and well-being. Give yourselves time to understand.”

“Do not judge every child by what you see on the outside. Beauty is not just what you see. All children have feelings and deserve a voice to be listened to.”

“It’s about trust. Establishing a relationship. Parents and children need to know that they can depend on the providers, and that they will be there for them. You need to get to know the child’s individual needs, as they are all different. Most importantly they are children in their own rights.”

You are not alone

1. Parents can help you. Parents of children with rare disorders tend to be the experts on managing a child with that condition.
2. Contact a Family can help you. There are hundreds of rare conditions and, because they are rare, you will probably only meet one of any type. *The Contact a Family Directory: Specific Conditions, Rare Disorders and UK Family Support Groups*, has over 350 condition entries covering over 900 rare disorders. The descriptions in *The Directory*, which have all been written by doctors, are parent-friendly and include details of parents support groups for the conditions.

If there is no family support group listed the Contact a Family **Freephone Helpline 0808 808 3555** can try to link families of children with the same condition.

You can view *The Directory* on the Contact a Family website <http://www.cafamily.org.uk>

Remember that some parents may not have ever heard of Contact a Family and may still be searching for information and contacts with other similar families. By referring them to the Contact a Family Freephone Helpline you would be providing the vital information and support they have been looking for.

Notes on the survey

The Contact a Family West Midlands undertook an 8 month project during 2003/2004 to help parents of children under 5 years of age with rare conditions access mainstream early years services in Birmingham.

Parents’ views were sought on their experiences of using mainstream services, through postal and telephone surveys and a workshop specifically for parents of children with rare disorders. 51 parents gave their views.



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Although great care has been taken in the compilation and preparation of this report to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.

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