



The Association for Children with Hand or Arm Deficiency

Patron: Laura Hamilton

An Introduction to Reach



You may have a child in your family with an upper limb deficiency or you know someone who has?

Reach is a support group run by families to give us the opportunity to meet others, offer advice and support.

Introduction

Hand or arm deficiency is relatively rare so many professionals involved in health care do not come across it very often, if at all.

'Reach' was founded in 1978 by parents of children missing part of their arm or hand. The formation of the Association was in direct response to the development of a new electronically controlled artificial arm. At that time, the most important aim was to press for provision of this technology to be available under the NHS.

It is now recognised that there are many other types of hand or arm deficiency where this, or other kinds of artificial limb are not applicable. Some children in 'Reach' are missing all or part of an arm, many others have partial hands or possibly malformed or missing fingers. Some may also have leg deficiencies.



The membership includes families with children of all ages from baby to teenager. A number of adults with limb deficiencies also belong to 'Reach', willing and able to offer the benefit of their experiences. Membership is open to anyone interested in furthering our aims and objectives including health professionals, friends and relations.

For many parents the birth of a child without an arm or a hand is a shattering experience which can leave you feeling isolated and alone. Rarely is there anyone who can really help or even start to answer all the questions that immediately press upon you:

- Why did it happen?
- How will he or she cope?
- What will happen to my baby?
- What do I do?

Certainly it was rare for parents to be able to talk to other parents who had gone through a similar experience. For many parents there was little or no guidance as to what the future might hold.

'Reach' has changed this, the Association has provided the means by which parents can be brought into contact with each other, giving them the opportunity to compare experiences and a means of understanding how others have coped or overcome problems. It can provide information on what to do and where to go for advice regarding treatment and has considerable knowledge and experience in supporting parents, health workers and all involved.

Many children and their families have found, since the formation of 'Reach' in 1978, that early and continued contact with others having similar experiences is of immense value.

What are the objectives of 'Reach'?

- To promote the interests and needs of children with upper limb deficiencies.
- Provide support and information to the families and carers of such children.
- To encourage and support research and development in the following areas:
 - (i) Upper-limb prosthetics and orthotics;
 - (ii) The causes of congenital upper-limb deficiency;
 - (iii) Surgical techniques relating to upper-limb deficiencies, liaising with the professional body or institution concerned.
- To develop and maintain a library of data and information in those areas relevant to the stated objects of the Association.

What does 'Reach' do?

- 'Reach' has a number of branches in various parts of the country which provide the opportunity for families to meet locally.
- 'Reach' publishes a newsletter 'Within Reach'. This provides a regular means of communication to all members families. The newsletters contain a wide range of information and articles on individual families experiences, new developments, details of Branch activities, fund raising efforts, etc.
- 'Reach' arranges insurance cover for the 'good arm' of children over two years of age in the Association (UK only). This cover is provided as an automatic benefit of membership.
- 'Reach' has donated substantial sums for research into new technology for the development of improved artificial arms, and into a major project to try and discover why some children are born without an arm.

It is fully expected that we will continue our involvement in these areas as well as continuing to expand in to other relevant areas.

First Reactions

With the advancement of Ultra Sound Scanning limb deficiencies are sometimes detected before birth and can cause additional worries for the parents to be. Early detection of this nature can have its advantages and disadvantages. It can be helpful in so much as it gives the families time to find out as much information before birth as possible and to prepare friends and relations as well as themselves. On the other hand it can add stress to the pregnancy as parents wonder if any other problems have remained undetected.

If you have given birth to or have been given a diagnosis of a child with a limb deficiency, you will know of the shock you have experienced. You have to deal with some very painful feelings depression, anxiety, loneliness and perhaps feelings of guilt and anger as well. You will also have to decide how to break this news to family and friends.



It is possible too, that you searched your mind over and over again trying to pin-point the cause of the deficiency, only to find yourself at a loss. You may even have blamed yourself, wondering if some previous action, in some way, could have caused your child's problem.

It is likely that your doctors asked you questions about any illness that you may have had in the past, or drugs that you may or may not have taken. This may have led you to believe that the doctors knew something but were withholding it from you. The reality is that the doctors cannot give you an answer because in most instances they themselves do NOT have the answer, only personal theories. Neither medicine nor science, as yet, understands just how or why a limb stops developing normally during pregnancy. Until they do they will continue to search. Remember that all through history there have been babies born with upper limb deficiencies of various degrees, and it is not just a modern day problem.

However all this does not stop parents blaming themselves, and if you find yourself continuing to agonise in this way, you should consider seeking help from another 'Reach' member or Counsellor. You deserve and need your peace of mind for your own happiness, the happiness of the family, as well as your child.

There are going to be times when you as parents will feel angry with your children, this is natural, you will feel angry because you are human. So if you felt angry when your child was born with a limb deficiency, it was also because you were human. You were gravely disappointed; you did not know how you would be able to cope. If you felt some initial 'drawing away', or had some difficulty in looking at the limb, you felt this too because you are a normal human being.

Confronted with something strange and inexplicable, it is no wonder that we experience these feelings; it does not mean that we do not love the child, or that we will not be good parents.

When your child is newly born, he/she is not yet developed, and as you lovingly watch your baby grow, change and learn to do things, you will rapidly forget all these feelings and misgivings.

Fears about the Future

You may find these either as a general worry and dread, or your fears may be specific. Lacking experience in dealing with your child's problem, you naturally do not know what to expect. You may find it difficult to conjure up the picture of your child going off happily to school, enjoying games with his playmates, or dating as a teenager.

Until you see your child develop some of his natural abilities, you may under-estimate his potential. The experience of members of Reach shows that the development of a child who has a limb deficiency is similar to the development of any other child. Your child will have some limitations, as every child has, but he/she will also have the capacity to adapt to his/her limitations and to find ways of accomplishing what he/she wants. Experiences narrated in 'Within Reach' constantly prove this.

Remember, none of us can predict the future, and I suspect would not want to, neither can you control it; you can only affect the present. Like all parents, you will find yourself pleasantly surprised as you watch your child grow.



Reaction of other people

Parents are often concerned about this and often worry about handling it. Actually, there is no magic formula or one 'right way'.

You will find through the passage of time, contact with other Reach families and by personal experimentation the way that is comfortable and right for you. You will soon become less anxious when dealing with other people.

Most parents find direct questions are the easiest to handle, e.g. if someone asks 'What happened to your child's arm?' You can simply answer 'He/she was born without a hand'. You may wish to say more, or you may not, depending upon the situation. Some parents find it easier to 'break the ice' by helping someone to express the question that you are sure is on their mind.

Nobody likes to be stared at, and you might find yourself becoming irritated if someone looks at your child for an extended period of time. Remember, however, that curiosity is human, it is the attempt to learn about what is new or different - you yourself do it all the time.

If you find yourself feeling angry, try not to be angry with yourself but be patient, you will gain experience and perspective and as a problem it will cease to exist.

Self Acceptance

Most parents are concerned with how other people's reactions will affect their child's feelings. The underlying question seems to be 'how can my child accept himself if he encounters negative reactions in others to his limb deficiency?' Self-acceptance means that we value ourselves as we are, with all our weaknesses and strengths, and regardless of them. It allows us to live, to enjoy and grow in spite of the frustrations and crises of life.

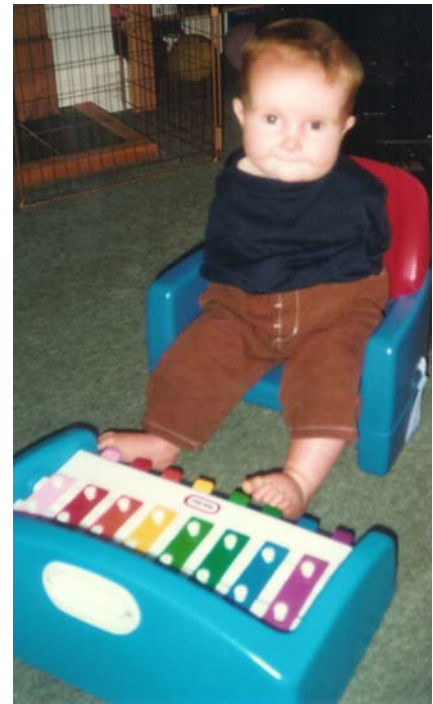
How then do you specifically help your child develop healthy attitudes towards himself? First of all, be clear on where your responsibility lies. You cannot feel your child's feelings for him, or live his life. Do not be over responsible, respond as best you can to his needs, and in doing so you provide the foundation on which he can build.

His needs are the same as they are for all children. Aside from the normal need for food, shelter, clothing and health care, he needs warmth and affection - the external evidence of your love for him. He needs education, recreation, friendship and respect for his individuality.

Life offers many opportunities for self development - allow your child to take advantage of them by neither over-protecting him or by demanding perfection.

Your Child's Questions

Before your child walks, you will notice his growing awareness of his own body. As a developing infant, he will discover his eyes, nose, extremities, etc., and some parents become unnecessarily alarmed as the child shows awareness of his limbs. They are afraid that he will feel badly when he sees a difference. It is a comfort and help to know that the child's discoveries do not mean he is making value judgements about them, as he does not have the intellectual ability at this early stage to judge one thing as lesser than, or more than, another. They may be your thoughts, they are certainly not his. Keep in mind that your child did not experience the emotions that you experienced when he was born, and try not to complicate the answers to his simple questions. If the young child wants to know why he does not have a hand, he wants an answer and a truthful one. The simple truth is that he was born without a hand. He is not preoccupied with the need to know the reason.



Some children ask questions, while others do not. If your child does not, do not see this as a sign of emotional disturbance. Children's personalities vary, and some may not feel the need to question. Do show them, however, by your own receptive attitude, that you are open to questions. As children observe the world around them, they see trees and flowers grow, and they notice their own growth, so a natural fantasy is that the affected arm or hand may yet grow to be complete. If your child asks 'Will my arm grow?', you can explain to him that his arm will grow in size, just as he will get bigger all over, but that he will not grow a hand.

If you have other children, you may be concerned about how they will react to the missing limb of their brother or sister. Most parents find that siblings are able to accept the child with little difficulty, but again, be open to their questions and realise they too may have natural fantasies about growth.

We would like to thank Darlene Talbot M.S.W. of the University of California for her permission to use text for this section from her booklet: 'The Child with a Limb Deficiency: A Guide for Parents'.

Teasing - See psychological aspects (p11/12)

Associated Syndromes

Although as stressed above, the cause of most limb deformities is unknown some hand or arm abnormalities are part of a genetic syndrome. The membership of 'Reach' includes families of children with the following syndromes:

- Radial Aplasia
- TOFS (Tracheo-Oesophageal Fistula Syndrome)
- Polands Anomaly
- Hypoglossia-Hypo-dactylia
- T.A.R. (Thrombocytopenia Absent Radius)
- Holt Oram
- Cornelia de Lange
- Hanhart
- Femur/fibula/ulna syndrome
- VATER (Vertebral/Vascular, Anal, Tracheo, Oesophageal fistula, Renal/Radial)
- Some with an acquired condition such as Erb's Palsy

'Reach' can provide information of these and/or contact with other Associations specialising in some of these syndromes.

Where do We go from here?

Where do we go from here? Who do we need to see? What treatment is available?

These are some of the questions parents often ask next and they can receive conflicting and confusing answers. The reason for this is the complexity of upper limb deficiency. Referral and treatment for a baby born with part or all of a limb missing will differ from that for a baby born with an incomplete hand. But in the first instance all babies born with congenital limb deficiencies should be referred to a Disablement Services Centre (or equivalent specialist Clinic for congenital hand problems). This referral should be made as soon as possible - within the first few months. Where the deficiency is spotted on an Ultra Sound Scan prior to birth, parents should be given the opportunity to visit the DSC. Normally referral will be made to the Centre nearest the families home, however, it should be realised that some centres have more experience and better facilities than others. Assessment by a multi-disciplinary team will ensure your child reaches full potential. Ideally this team should be experienced and trained to deal with the special needs of limb deficient children and should include:

- Rehabilitation Consultant,
- Prosthetist,
- Physiotherapist, (less frequently included)
- Occupational Therapist.
- Community Paediatrician



Other specialists your child may be referred to, depending on the nature of the deficiency include Plastic/Reconstructive/Orthopaedic Surgery for the improvement of function, or of appearance, or both. An Orthotist may also be involved in some cases.

Early referral enables the family and child to become accustomed to the centre and staff. Plans for the child's prosthetic or other care can be explored and a relationship begun. Early fitting of a prosthesis (if indicated) will help with the long term acceptance and ability to make an informed decision regarding limb wearing once your child is old enough. Any treatment you are offered for your child, be it the wearing of a prosthesis/artificial limb or corrective/reconstructive surgery, can have two implications; cosmetic or functional improvement. As a parent you will need to decide which of these is more important for your child. It is easy to believe that if an artificial limb is high tech. and cosmetically good to look at it must be the best choice, this is not always the case and parents should be guided by the team.

One of the first functional limbs your child may be offered is a split-hook. This device is not very pretty to look at but is extremely functional. It should be noted that this type of limb is often the one adult patients find most useful, so perhaps perseverance at an early age may be beneficial. It would be nice if our children were allowed to have both a split hook and a more cosmetic working hand. Some centres are still able to offer this, but budget restrictions may not allow this. You will also be amazed at how adept your child becomes at finding alternative methods of doing 'two handed' activities when not wearing their artificial limb.

Our Booklet 'A Guide to Artificial Arms' explains the possible forms of treatment in more detail. The Amputee Medical Rehabilitation Society issue recommended standards of care for congenital limb deficiency and parents should be aware of whether or not centres meet these standards.

Surgery

If surgery is offered the decision can often be even more complex (An artificial limb can be discarded or changed at any time, surgery is more difficult to alter). In these cases 'Reach' can provide support for families who are offered this form of treatment, this support includes:

1. Articles from and contact with other 'Reach' parents who have already accepted or rejected surgical options.
2. Articles from professionals working in the f
3. Clinical Notes on Pollicisation - the rotating of a finger to create a thumb.ield of Reconstructive Hand surgery.

We also recommend seeking a second opinion and here we can help in identifying a surgeon with experience in the technique being offered.

Description of Professionals:

Consultant in Rehabilitation

As head of the team he/she will have the knowledge/experience needed to assess your child's need. After careful consideration and consultation he/she will decide if a prosthesis (artificial arm) would be suitable and if so when and what to fit. It may not be necessary for him/her to see your child at every visit but he will reassess at regular intervals.



Prosthetist

If the consultant decides your child could wear an artificial limb, it is the prosthetists job to measure, prepare a cast and eventually fit your child's limb. They are also often very inventive people and if your child comes across a particular problem/task for which his artificial limb is not suitable a prosthetist can often suggest or make adaptations.

Occupational Therapist/Physiotherapist

Whatever your child's deficiency an OT or PT can often offer a wide range of assistance. They can suggest exercises and other simple devices to help your child to do day to day tasks. These can range from a simple wristband to slot in a knife, fork, pencil etc to splinting to correct some functional deficiencies. The OT will also be the person responsible for teaching your child to use any artificial limb. Support and advice can be offered to the staff when your child starts play-school or nursery and when he moves on to mainstream school.

Orthopaedic Surgeon

Some but not all Orthopaedic Surgeons have specialised in corrective surgery for congenital limb anomalies, and it is a specialist in this work that your general practitioner should find for you. He/she should and would generally be a member of a team. Should your general practitioner have difficulty, 'Reach' may be able to help.

Plastic Surgeon

Some but again not all Plastic Surgeons have specialised in hand and finger surgery. Whether an orthopaedic or a plastic surgeon should be consulted will depend on their respective areas of specialisation and their membership of a team. Once you have located an appropriate rehabilitation team, the appropriate referrals should be automatic. Again, in case of difficulty, 'Reach' may be able to help.

Community Paediatrician

This is a Consultant Children's Specialist, with special training in children's development and growth. He/she may not be a member of the Rehabilitation team, but should be included as he/she can be extremely useful, having knowledge of local nurseries, schools etc. The involvement of the Community Paediatrician becomes obligatory when a child is likely to require special facilities for education.

Orthotist

Where additional or specialised splinting is required.

Ideally, all or most of the above should have had the experience of working together for several years, dealing with at least 5-10 children such as yours each year. Should you live in an area where such experience would be difficult to come by, 'Reach' could, if asked, advise you or your general practitioner where the nearest Centre with such experience might be available for a second opinion. Any decisions and developments should be shared with your local Community Paediatrician.

It does sometimes arise that parents, having had contact with a Consultant previously, nevertheless would like to obtain a second opinion but find this difficult to ask for. The most appropriate step under these circumstances would generally be a discussion with their general practitioner, with or without the help of 'Reach' in case of difficulty.

Growing Up

Early Days

Full independence will be the most important aim for all the parents of children who have an arm deficiency whatever the type. This of course begins at home, with walking, talking, feeding, playing, dressing oneself and using the toilet.



Social interaction with other children is also important. Going to a mother and toddler group locally can be very useful, helping both parent and child to gain confidence to overcome all situations, it is different from being with family and friends. Meeting new people can help develop strategies for describing and talking about the deficiency. Your child will listen to how you describe the arm and copy later on, so being matter of fact and using simple terms will pay dividends. Involve your child in all the explanations. The child may also be with children he will go to school with later on.

Very young children will usually not notice any differences and just accept the deficiency. Slightly older ones and some adults will ask questions and this gives an opportunity to explain about the difference. Other adults are also curious but don't like to ask! By being open in your replies to direct questions the children will be satisfied. The adults will either overhear or learn from their own children later. Your child will learn to respond in the same way, without embarrassment. Once they see that you expect your child to be like everyone else they will put it to the back of their minds and your child can play like everyone else. Be honest and straight forward, children appreciate this and your child will learn too. If your child realises you and all around him can accept him without embarrassment, he will accept himself in the same way. If your child wears a prosthesis explain how it works - your child will probably be happy to demonstrate how it works, but don't push him if he isn't.

Pre-School

Obviously choosing a nursery school or playgroup is a very important step, it should be one that you feel will suit your child and offer the correct level of education. Meet the staff running the school and see if your child can go along for a morning and see how they treat your child. Are they worried, do they approach him as any other child, do they leave him to get on with the activities and play or do they watch him all the time? The response of the supervisors is particularly important. Ideally they should be prepared to stand back and observe your child's abilities, intervening only when help is obviously required. Discuss any possible problems, such as the need for straightening out clothing after going to the toilet, sand and water play if he wears a prosthesis. Be aware that any prosthesis may look unnatural and heavy to the staff and they may be wary, initially, about helping your child to take it off and put it back on. Make sure they are comfortable with this aspect of your child's life. Your local Occupational Therapist who knows your child may be able to help them. One other factor which should be borne in mind is the pre-school location in relation to the primary school you hope your child will attend. If he or she moves onto school as one of a group of children who are already comfortable with each other this will obviously be a great advantage.

Primary Education

It is a good idea to register your child well in advance and to mention the hand or arm deficiency at the same time. When further details arrive, ask if the school does home visits. These can be important to 'demystify' the situation as far as the class teacher is concerned. The teacher will see the child in his home environment and realise that the child can do most things, be it in their own particular way. This will help your child in the classroom situation because a teacher may be concerned about such a child entering her class. Not all schools will have home visits, but a request can be made to the head teacher who will probably be quite helpful and will agree. If a home visit is not possible, remember that your child's Occupational Therapist may help, and may agree to see the teacher. In any event, arrange for your child to meet his teacher as soon as possible. By the end of this initial visit the teacher should realise that apart from physical differences your child is like all the others, and can be expected to participate in all school activities. After all your child has coped this far with his/her deficiency. If there are any practical problems, remember that the Occupational Therapist attached to your local Disablement Services Centre has experienced knowledge of many methods, aids and appliances for overcoming these and can spend time with your child in school to assess and solve any problems. If the child wears a prosthesis, this should be explained to the teacher. A copy of our leaflet 'A Guide for Teachers' may be useful and is available from our head office.

Once at school it may be necessary for you to go into the classroom and explain to the other children and teachers about the arm and prosthesis, but take the lead from your child as some children may find this more embarrassing than one to one explanations in the playground. Be prepared to discuss worries and problems with the teacher; a good relationship works wonders.

Most children with a deficiency are more confident and independent than their classmates and will stick up for themselves and cope extremely well. The other children may be curious and may well give your child rather too much attention, even offering to help your child when he doesn't need it. This attention will diminish, especially if your child is clear in his answers and shows he requires no assistance. They may be fascinated by his arm but will rarely be embarrassed or hurtful. This kind of attention should not be confused with bullying which is a rare occurrence and would appear, when it does happen, to often have nothing to do with the arm at all! However, if bullying is experienced it needs to be tackled promptly as it is easy for it to erode your child's confidence.

Transition to Secondary School

There is usually a well-tried system to make the transfer to secondary school as painless as possible for all pupils. Pupil records will be passed on and perhaps introductory visits will take place. Parent meetings and information forms will enable you to ensure that the school is aware of your son or daughter's limb deficiency. Once again stress your child's physical abilities and dexterity. There may, however, be times during practical sessions in science, domestic science and technology lessons and with physical education, when some allowances need to be made - from both sides. It is worth remembering that the Occupational Therapist will be willing and able to assist in answering practical problems. A school visit can take place if requested.

Statementing - for the Minority

When a child has a bilateral upper limb deficiency or both upper and lower limbs affected there may be a need for additional assistance within the school. This may also apply where a child has additional physical or learning disabilities together with a unilateral arm deficiency.

In these cases an assessment of the child's abilities by the Educational Authority should lead to a Statement of Special Educational Needs which results in the child receiving appropriate help within the school environment or at a special school. The Community Paediatrician will generally initiate this.

A very useful fact sheet 'A Parents Guide to Statements of Special Educational Needs' is available from our head office.

Psychological Aspect

Babies and very young children are unlikely to have any psychological problems associated with their limb difference. Parents may have difficulties adjusting to their child's physical difference. It is important to get help and support in coming to terms with this. Positive parents are more likely to have positive children with high self esteem. If we as parents can naturally accept our children, difference and all, they in turn will have no problems accepting themselves.

At some time in most children's lives, whether they have a limb deficiency or not they will go through a stage of self consciousness (usually between 6-9 years). At this age children want to be like other children and be accepted by their peers. Physical issues like appearance and clothes can become very important. It is at this time when some children may begin to try to hide their deficiency, even though they have accepted it in the past. They may for the first time show signs of resentment and feel a sense of injustice - why me?? They are striving to make sense of themselves, and if there are problems, then calm and sympathetic discussions with parents can help them through this time. They are also now able to and need to understand that they are how they are and that no "magic" will change that. It may also help to point out that how they are may have helped to make who they are! If children and parents find it difficult to talk through these times it can often be helpful to enlist the help of a relative, friend or teacher. The child's development of his or her self-concept is dependant on many factors, but the crucial ones are the acceptance and love of those closest to him. On that foundation, the family can help the child through treatment, limb fitting, therapy and any surgery which may enhance his abilities.

Teasing can be very hurtful, and most school children experience it at some time. Remember, almost all children are teased by other children for anything that may appear "different", such as wearing glasses, red hair, braces. It is often the response to the teasing that will tend to make it worse, or become less frequent. Some children benefit from being helped to deal with this. Once again a quick response can often calm the situation and if the child's self worth is in tact most of this form of teasing will be brushed aside. However, if the teasing becomes more acute and leads to actual bullying, either verbal or physical, this must be addressed swiftly. It is easy for children with a deficiency to become 'natural victims', they can begin to believe they deserve to be bullied because they are different. All schools should have an anti bullying strategy and this must be used to its

full capacity if necessary. Parents should initially approach the class teacher, going on to the Head teacher and if the problem persists they should then enlist the help of School Governors and their local education authority.

As children reach adolescence, then both function and appearance are important. If things have gone smoothly up to now, it is likely that they will have the strength of character and inner resources to come to terms with the emotional and physical demands of adolescence, although there are no guarantees that our physically different children will be any easier to cope with than other typical teenagers.

Children who lose a limb following an accident or selective surgery often find it more difficult to come to terms with, unless they are very young at the time. They can be far more difficult to motivate and discipline than those born with this condition. They will need help to accept their new 'body image' and may not be able to move on until they do.



In conclusion

There may be problems that crop up at different times in a child's development, but they can be solved.

'Reach' plays a vital role in supporting parents and thus their children, and smoothing the path to a happy and well adjusted adulthood. So if and when you need help we will be there.