



Pediatric Myoelectric Fittings

by Jack Uellendahl, C.P.O.

Director, Rehabilitation Institute of Chicago Prosthetic-Orthotic Clinical Services

The past decade has seen tremendous change in the fitting philosophy for children with upper limb deficiencies. This change has been spurred on by improvements in hand terminal devices and the electronics that run them. Ten years ago, a one-year-old child would not have been considered a candidate for a powered limb. Hands were not appropriately sized for a child this small. Today such fittings are common.

Up until now, more powered components have been developed specifically for children rather than for adults. This is an incredible fact when one considers that smaller components are usually harder to develop and there is a limited number of upper limb amputees who can buy

them. This explosion of component choices has been led by Variety Ability Systems, Inc. of Canada. They currently produce three hands, three elbows, and a wrist rotator for children. The hands are sized to allow fittings of children less than one year old, with the largest hand rated to fit a nine-year-old child. Other manufacturers involved in producing child-sized powered hand components are Steeper of England and Otto Bock of Germany.

The contemporary protocol for fitting a congenital upper limb-deficient child calls for a passive "crawling arm" to be fitted at three to six months of age. This is based on the child's attainment of certain developmental milestones; namely, when the child achieves sitting balance.

This first arm has no prehension (grasp) function of the hand and is intended to provide a passive, two-handed opposing "grab", as would be used to hold a large ball or a cuddly teddy bear. It also serves to get the child used to wearing a prosthesis.

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A myoelectric hand being evaluated on a 3-year-old. The arm is in a trial set up to evaluate fit, comfort, and control. She seems pleased with her early success at opening the hand. The bear wears a body-powered hook.

Pediatric Orthotic Management

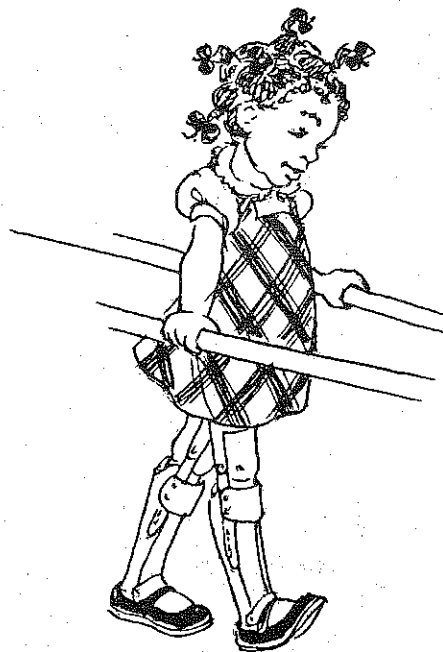
by Laura Fenwick, C.O., Director, Orthotic Education & Bryan Malas, Instructor, Clinical Orthopedic Surgery
Northwestern University Medical School Prosthetic-Orthotic Center

Children possess a remarkable ability to adapt to their limitations, and when disabled, show an overwhelming desire to work beyond their disability. It is this desire that makes pediatric orthotic management so rewarding. Pediatric orthotics differs from adult management in many respects. A child is continually growing, intellectually as well as physically. This poses a continual challenge for the orthotist to maintain an intimate orthotic fit despite growth and to adapt orthoses to allow age appropriate function. The dynamic nature of childhood should be represented in the orthoses which children use.

When do we orthotically manage pediatric limbs? The instances are many and varied, but include developmental abnormalities of the limbs, as well as specific conditions of childhood. Cerebral palsy, spina bifida and muscular dystrophy show orthotic needs, although each condition and child affected has unique requirements. Congenital malformations of the limbs are commonly treated orthotically as well.

Considerations

When managing developmental abnormalities, the practitioner must be knowledgeable about normal growth and alignment of the lower limbs. Children develop adult gait by the time they are five to seven years old. As the child develops adult gait, his legs assume their adult appearance. For example, infants have approximately 5 degrees of genu varum (bowleggedness) when they are born, and as they begin to walk the legs correct, then overcorrect to a position of 5 degrees genu valgum (knock-kneed). The knock-knee trait should resolve itself by the time a child is 7 years old, when the child's legs should appear straight. The parent of a two year old may be distraught by the bowed appearance of his child's legs, but bowing is normal for his age. It is the practitioner's responsibility to discuss when orthotic management is necessary and to utilize appropriate management. The primary indication for a pediatric orthosis is to prevent deformity. For an orthosis to prevent deformity, the orthosis creates a system of forces that act on the involved body segment. Whether for support, stabilization or correction, all orthoses work on this principle.



Cerebral Palsy

Normal development of a child's lower limbs occurs as a result of a balanced reflex system, limb alignment, and proper locomotor skills. When any of these are compromised, orthotic management may become necessary. Children with cerebral palsy often exhibit deficits in one or all of these areas. This non-progressive condition is characterized by abnormal muscle tone, muscle asymmetry, impaired balance and loss of selective motor control. Cognitive function varies significantly from child to child. A primary orthotic complication in cerebral palsy is joint contracture (permanent contraction of a muscle due to spasm). Orthotic management thus depends on a thorough evaluation of each individual child. To create a biomechanically sound gait pattern, these children are typically fitted with varying styles of ankle foot orthoses (AFOs). Current trends in tone reduction, crouch control and supramalleolar (above the

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ankle) orthoses all address the characteristics of walking with cerebral palsy.

Muscular Dystrophy

Duchenne muscular dystrophy, a genetically transmitted condition, is characterized by progressive weakening of the skeletal muscles as they grow. Primarily affecting male children, as the muscles get weaker, children lose the ability to walk. These boys are treated and followed up closely to ensure the prevention of contractures that prevent walking, and fitted with orthoses to maintain good alignment of the lower limbs. Alignment considerations for the duchenne child are of utmost importance, as their weakness creates a delicate sense of balance that is easily disrupted. Lower limb orthoses are specially designed and assist these children to continue walking as long as possible.

Spina Bifida

Spina bifida management varies with the age and level of spinal injury. As with any childhood disability, the goal is to allow the child to perform age appropriate activities, either through or despite the use of orthoses. For example, a child between the ages of 6-9 months should be sitting up; in spina bifida the child of this age group might wear a TLSO (thoraco-lumbar-sacral orthosis) to enable sitting despite scoliosis, spinal injury and paralysis. By 12-15 months, as other children are beginning to stand and walk, children with spina bifida are fitted in standing frames to allow standing activities. Through these efforts, children are able to interact with their peers.

Summary

Spina bifida, cerebral palsy and Duchenne muscular dystrophy are just a few disabling conditions that may warrant orthotic management. Decreased painful motion and protection of weak muscles and ligaments are strong indicators for orthotic management. As discussed, the primary indication for a pediatric orthosis is to prevent deformity. Deformity prohibits function, and age appropriate function is the key to intellectual development. It is the responsibility of the uniquely qualified pediatric team members to evaluate, recommend and effectively manage the variety of orthopedic pediatric problems we see today. ♦

Drawings on pages 2 and 5 by Dot Yoder. Used with permission from the book, "Patrick and Emma Lou," by Nan Holcomb and published by Jason and Nordic Publishers, Exton, P.A.

Consumer View

A Young Adult from Atlanta Speaks about Disability

When I was born, I had a club foot and was missing several bones in my hip and left leg. At 8 months old, my parents decided to have my foot amputated. When I was 1 and 1/2 years old, I was fitted with my first prosthesis. This prosthesis was straight with no knee. I learned to walk with a toy grocery cart like you see now at the grocery stores. My mother took off the orange handle and filled it with toys. It only took three weeks and I was walking by myself without any help. At eight years old, I had a knee fusion so I could be fitted with a bendable leg. Then, last year, I was finally able to be fitted with a smooth leg that looks real. Everyone calls it my bionic leg!

I have had my ups and downs in my 15 and 1/2 years. Having sixteen major surgeries has made me respect the medical profession. Most of my hospital stays were good. The nurses and doctors treated me very well. I did get to know Scottish Rite Children's Medical Center very well. Even the janitors knew me. I celebrated one whole year with no hospital stays this past November. I am trying to keep that going.

When I started school, I was scared of what kids might say. I try to stay positive and I try not to let anything get in my way. I've taken gymnastics, acting lessons, and clarinet lessons. My leg doesn't get in my way with friends or boys. They don't even notice that I have a limp. I'm treated like anyone who has two legs.

I have a positive outlook on life. I'm a freshman at Norcross High School and I love it. I made the honor roll my first semester. My goal in life is to become a nurse and work with children, hopefully at Scottish Rite Hospital here in Atlanta. I think everyone has something about him or her that bothers them; whether it be the way their hair is going that day, a mark on their face, shyness, their height, weight, or color of their skin.

My advice to everyone is: *stay positive and don't let your disability, no matter what it is, interfere with your goals.* It might take a little longer to make the goal, but everything is reachable.

Remember you can do whatever you want to do if you set your mind to it, no matter what your disability.

Sincerely, Lisa Wetsel ♦

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The next arm will be provided at age 12 to 15 months. This hand will provide grasp function which is controlled myoelectrically. Myoelectric control uses an electrode mounted in the prosthetic socket which has direct contact with the surface of the skin, in order to pick up electrical signals normally produced by a contracting muscle. It is amazing to watch a child newly fit with his first myoelectric hand as he opens and closes the hand, quickly learning the control actions. If we compare this to the previously used body powered hooks which often take months to learn how to control, the improvements provided are very dramatic. Integral to this ease of operation was the development of a special electronic circuit called a "cookie crusher," requiring only one muscle action to open and close the hand. The child quickly learns that by contracting the muscles in his residual limb, the hand will open. When he relaxes his muscles, the hand closes automatically.

A child will usually continue to use the "cookie crusher" control until age three to four years. At this time they can be taught the more complicated, but more functional, two-site myoelectric control. The two site system uses two opposing muscle groups to control the hand. Generally, the muscles on the outside surface of the forearm open the hand and the ones on the inside surface close the hand. This is the normal function of these muscles, and therefore, is considered a natural or physiological control scheme.

The two site system is used throughout adulthood with progressively larger hands to match the size of the intact opposite limb. Presently, the two site system running a hand in a variable speed fashion is considered a "state-of-the-art" prosthesis. In the future, it may be possible to control more hand and wrist functions using more sophisticated electronics. Prosthetists, engineers and therapists are constantly striving for prosthetic designs which will be the most cosmetic and functional, better serving the needs of the limb-deficient child. ♦

One alternative is the CAPP terminal device.



Alternative Pediatric Prosthetic Fittings

by Yoshio Setoguchi, M.D.

Shriners Hospital for Crippled Children, Los Angeles Unit

For children with unilateral upper extremity limb deficiencies or amputations, especially at the below- or above-elbow levels, body powered prostheses should be considered as alternative prosthetic fittings.

Today, both the family and the professional are concerned about cosmesis for the limb-deficient or amputee child. When some function can also be provided, it is natural that they would like to see that child fitted with the most "high technology" device available. With the refinement of myoelectric systems and the availability of child-size hands, there is a tremendous urge to fit children with myoelectric prostheses. Unfortunately, due primarily to financial reasons, many patients are not eligible. However, even if funds are available for all children with unilateral limb deficiencies and amputations, there is still some question as to whether it would be cost-effective to fit all children with this type of prosthesis.

At the Shriners Hospital for Crippled Children, Los Angeles Unit, we have recommended initial fitting with a body powered system using either one of three types of terminal devices: the Dorrance Hook, CAPP T.D. (terminal device), or mechanical hand. Then, based on the consistency of wear and use, the family's cooperation in following through with therapy, and the family's willingness to follow through with prosthetic maintenance, we consider myoelectric fittings when the child is three to four years of age. If the patient and family do not meet the above criteria, we feel that the chances for successful prosthesis wearing is much less, and therefore, do not approve the child for myoelectric fitting.

The concept that early fitting with myoelectric prostheses is essential for prosthetic wear and use has not been well documented by other clinics who have fitted children. If the child is a good functional user of a body powered prosthesis, it does not matter when the child is transferred to a myoelectric fitting. The child will do well. Children with poor previous prosthetic fitting and use *usually* do not do well with a later myoelectric fitting.

If one is to consider a body powered prosthetic fitting, it is important that the right prosthetic fitting and components are chosen. In the infant below-elbow fitting, a well-fitting harness that allows full range of motion of the shoulder joint is essential. Therefore, the CAPP chest strap harness developed by Mr. Carl Sumida at UCLA is

used. Also, the functional benefits of the prosthesis are increased by a frictional sleeve on the below-elbow forearm segment. We have chosen to fit children with the CAPP terminal device for the first fitting. It does not have a "hand" shape, but is flesh-colored and provides grasp function. When the patient is ready for an active terminal device, the same one is used. Our children have few problems adapting to this device if the adults around them accept the prosthetic system.

Success of a prosthetic fitting is *not* based on the type of prosthesis, but on the acceptance by, and support and encouragement of the parents and family of first, the child, and then, the prosthetic fitting. If the family is expecting a "perfect" replacement of the missing hand or arm they will often be discouraged, and this will be reflected in the child's response to the prosthesis. Once the family gets over that unrealistic expectation, the functional gains become the major issue and a body powered prosthesis is a very good option. ♦



Advocacy

Parents and Children Coping with Disability: The Parents' Reaction, The Child's Reaction

by Linda Lee Ratto, M. Ed.

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Understanding the normal progression of grief is an essential cornerstone in the healthy adjustment of a family with a limb deficiency:

1. Shock/denial/isolation
2. Anger/hate
3. Bargaining/Let's make a deal/guilt
4. Sadness/depression
5. Acceptance
6. Hope

The Congenital Amputee

The parents and family members are initially the ones who go through the grief after a limb-deficient child is born. The dream child, the unborn perfect baby is not a reality. This death of a dream IS a death. Along with the joy of birth comes the shower of emotions and feelings accompanying significant loss. These stages of grief are rather predictable and quite normal, according to E. Kubler-Ross in her book, *On Death and Dying*. Healthy adjustment to the newborn is a process which can take many years, as parents realize gradually what their child can do. At first, however, these stages may be experienced in close succession or even backtracking

perhaps experienced depression, then days of hope, followed by new days of depression.

If there is not a gradual grief progression, some parents may remain "stuck" in a stage. Not being able to grow out or through a stage is a sign for a parent to seek some help. For instance, remaining angry year after year can create a tremendously negative environment for the child. It is best for the baby and the entire family for the parent to grow through the grief process. Another example of stagnation is accepting the situation of the child, but with depression and hopelessness. If this continues for a very long time, the child will feel hopeless as well.

Even though it may sound almost harsh, there is more to life than the amputation. The child's mind and soul must still grow...

Reading, seeking to know, speaking with healthcare professionals will foster parental growth. Finding other parents who have similar experiences is also a necessary part in raising a special needs child.

As the baby matures toward adolescence, there seems to be a normal shift from the parents adjusting to the amputee situation to the amputee beginning his or her individual grief process. Put off for years by the very fact

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that the child knows no other way of life, the teen is now coming to understand what is and what is not, especially in relation to others. As with all adolescents, the amputee grieves over the "imperfect" form with which he or she has been born.

I use the stages of grief as a reference for all people in any significant personal challenge (cancer, heart attack, acute or prolonged loss of health, divorce, death of a loved one, etc.). Realizing grief as a normal life process makes it clear that the limb deficient young person will, and by all means should, go through his or her own grief. Depending on the level of the child's self-esteem, the stages of grief may be experienced quickly or linger. But for the most part, adolescence is a period of approximately seven years when one may expect the descents and ascents any young adult experiences. Coupled with amputation, the teen years can feel a bit like treading water or frustration at achieving two steps forward with one step back.

Traumatic Injury or Disease-Related Amputation

When the child has been born with all his limbs and loses one, the shock is immediate and the grief intense. As the young person struggles to regain health and get back to daily life, the family is forced to struggle too. Each member lives his/her pain and must adjust on his/her own terms. What happens to one family member, happens to all other in the family unit.

Parents often have no time to consider how well they are adjusting, since daily living needs are the priority. Other members of the immediate family such as siblings and grandparents, aunts and uncles are there for loving support, but also have their personal grief with which to cope.

The most significant need to be realized during the adjustment process is the need for every single person in the family—including the amputee—to have time alone. Time must be allotted to think, to simplify the day. Traumatic amputation is life-threatening. The patient is jolted face to face with death. Indeed the limb has died. If time is not set aside to think, to have "time-off" from it all, serious side effects can occur. Even though it may sound almost harsh, there is more to life than the amputation. The child's mind and soul must still grow, must be allowed to live and breathe. This holds true for every family member no matter what the age.

In my work as a parent, patient, educator, author, and rehabilitation consultant, I find the most effective tool in living with grief is the incorporation of others into my

experience. Whether you are a parent, professional, child patient, congenitally affected by limb deficiency or traumatically caused, people are the key to a healthy experience. Perhaps the most interesting constant in our lives is the fact that there are so very many people on earth. They are here for a reason. When we alienate ourselves, we lose perspective.

Limb loss is a personal tragedy. However, any person bares his/her own personal trauma. We can relate to each other in these struggles. Whether a professional, patient or family member, we are all human—sharing this journey called life. ♦

Ms. Ratto is currently writing a parenting book entitled: I'm a Person First! A Parent's Guide to Raising a Special Needs Child, due out in early 1994. More information on the topics addressed in this article can also be found in her two books, Coping with Being Physically Challenged and Coping with a Physically Challenged Brother or Sister, both from Rosen Publishing Group, New York, 1-800-237-9932. Ms. Ratto is a member of Northwestern University's Rehabilitation Engineering Program's Consumer Advisory Panel.

Review

Books for Children on Disability

A helpful pamphlet, "Tips for Selecting Books for Children with Disabilities," has this to say on the topic:

"Hopefully, the disability has not been focused on except as it is a crucial part of the story. Scan this list for words which are:

INAPPROPRIATE

partially sighted
handicap
able bodied
birth defect
dwarf
mute

APPROPRIATE

visually impaired
disability
nondisabled
congenital disability
small stature
person without speech

The *person* always comes first. The *girl* who is blind. The *child* who has a speech disorder. The *boy* who is deaf.

There are more than 100,000 children born each year with major birth defects. They are children with a need to be noticed, to be understood, to be talked to, to be praised or scolded as occasion demands. They will all have feelings of frustration and *why me* at some time. Many will never voice these feelings because they are unable to communicate. What better opportunity is there to know that these feelings are acceptable and



shared by others than through the wonderful world of books."

For additional copies of this helpful pamphlet, write to Jason and Nordic Publishers, P.O. Box 441, Hollidaysburg, PA 16648. For a comprehensive list of children's P&O resources (merely sampled below), write to the Resource Unit, NU-REP, 345 E. Superior St., Rm. 1441, Chicago, IL 60611 or call 312-908-6524.

Info includes title, author, publisher, ISBN (if known), city and copyright, small description, and ordering information if available.

For Children

Captain Hook, That's Me, by A. Litchfield
Walker and Co., New York, 1982.

Judy worries about the kids in her new school staring at her hook. Story tells how her worries are resolved.

Capt'n Smudge, by R. James & S. Cosgrove
Price, Stearn, and Sloan.
Amputee sea captain.

Danny and the Merry-Go-Round, by Nan Holcomb
Turtle Books, 814-696-2920.
Boy is distressed because disability keeps him from playground equipment.

Fanny, by R. James & S. Cosgrove
Price, Stearn, and Sloan, ISBN 0-843114606
Being handicapped is a state of mind.

Harry & Willy & Carrothead, by J. Caseley
Greenwillow Press, New York, ISBN 0688094929
Beginning reader about myoelectric hand.

Josephine, the Short-Necked Giraffe, by Mr. Rogers
Family Communications, 1975, ISBN 083310036X
Being glad to be YOU.

Patrick and Emma Lou, by Nan Holcomb
Turtle Books, 814-696-2920.
About the physically disabled.

A Smile from Andy, by Nan Holcomb
Turtle Books, 814-696-2920.
Feelings of inferiority are explored.

Someone Special Just Like You, by T. Brown & F. Ortiz
Holt, Rhinehart and Winston, New York, 1984.
Picture book on special children being kids; wearing leg brace, wheelchair children, using a walker, etc.

For Teens

Coping with Being Physically Challenged
Coping with a Physically Challenged Brother or Sister
Both by L. Ratto. Order from Rosen Publishing, New York,
1-800-237-9932.

Izzy Willy Nilly, by Cynthia Voigt
Anthaneum Books, New York, 1986.
Teen loses her leg in an accident.

The One Armed Gymnast, by C. Johnston
Children's Press, Chicago, 1982.
Real life story of one armed gymnast who was named all-American.

Peter Gray: One Armed Major Leaguer, by W. Nicholson
Prentice Hall, Englewood Cliffs, 1976.
Story of a boy who became a professional ball player after losing his arm at age 6.

PS Write Soon, by Colby Rodowsky
Farrar Straus Giroux: Sunburst Ed., 1987.
Lib Congress No. 87-19621
Story of a 12-year-old girl who wears leg brace.

Rajesh, by C. and G. Kaufman
Athaneum Books, New York, 1985.
Experiences of a young boy with congenital limb deficiencies.

General

Accept Me as I am: Best Books on Juvenile Non-Fiction on Impairment & Disabilities
by J. Friedberg. Published by RR Bowker, New York, 1985.
Annotated book list of juvenile fiction portraying disabled people, 1940-1984.

Attitude Toward Disability:
A Bibliography of Children's Books
Pediatric Products, PO Box 2175, Santa Monica, CA 90406.

Siblings: A Bibliography of Children's Books
Pediatric Products, PO Box 2175, Santa Monica, CA 90406. ♦

Resource Unit for Information and Education
NU-REP, 345 E. Superior St., Rm. 1441, Chicago IL 60611

Resources for children and parents together in P&O are many and varied. The list below includes publications, support organizations, and other helpful information focusing on pediatric issues. This material is excerpted in part from the Resource Unit's 1992-1993 Prosthetic-Orthotic Resource Directory, available free by contacting the Resource Unit. Other children's resources are also available.

Organizations

Amputee Coalition of America

6300 River Rd., Suite 727, Rosemont, IL 60018
Phone 708-698-1628.

Area Child Amputee Center

235 Wealthy St., Grand Rapids, MI 49503
Phone 616-454-7988

Association of Birth Defect Children

5400 Diplomat Circle, Suite 270, Orlando, FL 32810
Phone 407-629-1466

Association of Children's Prosthetic-Orthotic Clinics

222 S. Prospect Ave., Park Ridge, IL 60068

Avenues

P.O. Box 5192, Sonoma, CA 95370
Phone 209-928-3688

BDIS (Birth Defect Information Services)

Dover Medical Bldg., Box 1776, Dover, MA 02030
Phone 508-785-2525

Center for Children with Chronic Illness

University of Minnesota, Box 721
Harvard at East River Road, Minneapolis, MN 55455
Phone 612-626-4032

Child Amputee and Prosthetics Project

UCLA Medical Center, Dept. of Pediatrics
12-441 MDCC, 10833 Le Conte Ave., Los Angeles, CA 90024
Phone 310-825-5201

COPH (Congress of Organizations of the Physically Handicapped)

P.O. Box 7701, Chicago, IL 60680

Easter Seal Society

70 East Lake Street, Chicago, IL 60601

March of Dimes

1275 Mamaroneck Ave., White Plains, NY 10605

Muscular Dystrophy Association

3300 East Sunrise Dr., Tucson, AZ 85718
Phone 602-529-2000

National Center for Youth with Disabilities

University of Minnesota
420 Delaware St. S.E., P.O. Box 721, Minneapolis, MN 55455
Phone 612-626-2825

National Scoliosis Foundation

72 Mt. Auburn St., Watertown, MA 02172
Phone 617-926-0397

National Spinal Cord Injury Foundation

1032 La Grange Rd., La Grange, IL 60525
Phone 708-352-6223

PACT

Kessler Institute for Rehabilitation
Pleasant Valley Way, West Orange, NJ 07052
Phone 800-648-0296

Parent to Parent

2939 Flower Road South, Atlanta, GA 30341

Scoliosis Association

P.O. Box 811705, Boca Raton, FL 33481
Phone 800-800-0669

Spina Bifida Association

6 South 211 Cape Road, Naperville, IL 60540

SUPERKIDS

60 Clyde Street, Newton, MA 02160
Phone 617-964-2244

United Cerebral Palsy Organizations

1522 K Street N.W., Washington, DC 20005
Phone 202-842-1266

Publications

Adolescents with Limb Loss: A Handbook for Adolescents and Their Families

Grand Rapids: Area Child Amputee Center, 1990.

Cherub Forum Newsletter

Assoc. of Families & Friends of Limb Disorder Children,
716-878-7551.

Children with Hand Differences: A Guide for Families

Grand Rapids: Area Child Amputee Center, 1990.

Children with Limb Loss: Three Handbooks for Families

Grand Rapids: Area Child Amputee Center, 1990.

Connections

Nat'l Center for Youth with Disabilities, University of Minnesota, Box 721-UMHC, Harvard St. at E. River Rd., Minneapolis, MN 55455.

Special Parent, Special Child Newsletter
South Salem: Lindell Press, P.O. Box 462, South Salem, NY 10590.

SUPERKIDS Newsletter
Superkids, 60 Clyde St., Newton, MA 02160

Exceptional Parent Magazine
605 Commonwealth Ave., Boston, MA 02215

Anderson, FJ. *Self Concept and Coping in Adolescents with a Physical Disability*, Issues in Mental Health Nursing 4: 257, 1982.

Buscaglia, L. *The Disabled and Their Parents: A Counselling Challenge*, Thorofare: Charles B. Slack, 1975.

Cammack, S. *Integration of Pediatric Amputees and Their Parents with an Adult Amputee Support Group*, JACPOC 24(1): 6, 1989.

Demaio, D. *Body Image Concerns of a six-year-old Boy*, J. Clinical Nursing 175, Fall 1978.

DesJardins, C. *How to organize an Effective Parent Advocacy Group and move Bureaucracies*, Chicago: Coordinating Council for Handicapped Children, 1980. Order from 407 S. Dearborn, Room 680, Chicago IL 60605.

Featherstone, H. *A Difference in the Family: Life with a Disabled Child*, New York: Basic Books, Inc., 1980. Order from 10 East 63rd St., NY NY 10022.

Fernandez, HC. *The Child Advocacy Handbook*, The Pilgrim Press, 1980.

Gilmore, J & E. *Give Your Child A Future*, Englewood Cliffs NJ: Prentice Hall, 1982. Cultivate self esteem and values in your school age child.

Koelker, T & Labhard, S. *Hal Gets a Prosthesis*, Portland: Shriners Hospital, 1989. Video for children and parents on getting a prosthesis. Can be used with a Hal Doll. Order from AFTER, 8408 West McNab Rd, Tamarac FL 33321.

McCallum, AT. *Grieving over the Lost Dream*, The Exceptional Parent 9, February 1984.

Mercer, RT. *Crisis: A Baby is born with a Defect*, Nursing 45, November 1977.

Meyer, D & Fewell, R. *Living with a Brother or Sister with Special Needs*, Seattle: University of Washington Press, 1985.

Miezio, PM. *Parenting Children with Disabilities: A Professional Source for Physicians and a Guide for Parents*, Levittown: Phoenix Society, 1983.

Routburg, M. *On Becoming a Special Parent: A Mini Support Group in a Book*. Chicago: Parent/Professional Publications, 1986. Order from P/P Pubs, P.O. Box 59730, Chicago, IL 60645.

Sabolich, J. *You're not alone*. Sabolich Prosthetic and Research Center, 1991. Order from 800-522-4428.

Smith, PM. *You are not alone: for Parents when they learn that their child has a handicap*, Washington: NICHCY, 1984. Order from NICHCY, P.O. Box 1492, Washington DC 20013.

Stein, SB. *About Handicaps*, New York: Walker and Company. ISBN 0-8027-6147-7.

Suderman, V & Tervo, RC & Leszczynski, J. *Patient and family perceptions of a juvenile amputee clinic*, Interclinic Information Bulletin 18: 1, 1982.

Talbot, D. *The Child with a Limb Deficiency*, UCLA Child Amputee Prosthetics Project. Order from 1000 Veteran Avenue, Rm. 25-26 Rehab Bldg., Los Angeles, CA 90024.

Thompson, C. *Raising a Handicapped Child*, New York: Wm Morrow & Company, Inc., 1986.

Zuckman, J. *Kids Plus—Group helps parents of some special kids*. Order from Kids Plus, 4191 Kennedy Circle, Colgate, WI 53017. ♦

Resource Unit Information Request

Fill out the information below, then send this coupon to:

Northwestern University
Rehab Engineering Program
Resource Unit for Information and Education
345 E. Superior St., Room 1441
Chicago, IL 60611

☐ Please send me more information on lab activities.

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What Users Want

Part 2: User Opinions

by Else M. Tennesen, M.S.

In the fall of 1992, the Resource Unit disseminated a questionnaire entitled, "The 1992-1993 Resource Unit Prosthetic-Orthotic Survey: What Users Want." Results of a portion of this survey—namely, the ranking, true and false, and statistics sections—were reported on in the January 1993 issue of *Capabilities*. Please see this issue for logistical information on the distribution of this survey. This report will endeavor to report the results of the *Sentence Completion* portion of the survey, as well as implications of the results.

In the *Sentence Completion* portion of the survey, users were asked ten open-ended questions which solicited their opinions on practitioners, information needs, personal needs, and conceptions about prosthetic-orthotic users.

For each question, each response was placed in a category. The categories were determined by the number of times an issue was mentioned by respondents. The number of times each category was mentioned was totalled, and then the categories ranked. For each question asked, then, there evolved a number of answers that came up the most frequently, and reflect the users' opinions. The ranked responses are shown below with their associated question.

There were cases where some responses were considered invalid (not counted). For example, if the question was left unanswered, it was not tallied. If an answer was provided which did not relate to what the question was asking, it was not tallied.

QUESTION 1 (115 respondents). The thing my practitioner does best is...

"My practitioner takes time to discuss developments in prosthetics that might benefit me, and is willing to suggest different limbs that might work for my situation..."

"Treats me like a normal person instead of a number or a patient; i.e., says Hi, uses my name, is warm and friendly, etc. He asks how I'm doing—not just my feet, but ALL of me."

"Listens to what I have to say about what works for me and my needs. We talk about what works and what does not. He is willing to work with me and try new ideas."

"My practitioner does well in the fitting process and giving helpful information."

These sample responses typify the four top ranking categories of

- (44) Practitioner expertise; skillfulness; makes comfortable devices
- (28) Quality of service and practitioner availability
- (22) Good "bedside" manner
- (19) Gives information.

The remainder of responses frequently mentioned included: practitioner allows patient involvement; practitioner has good follow-up; practitioner remains current in state-of-the-art advancements; and practitioner practices good cost management (devices/services not excessively expensive).

QUESTION 2 (62 respondents). The thing my practitioner does worst is...

"My practitioner does not consider my feelings and suggestions in the selection of the device's design.

"Doesn't listen to me about how my leg feels.

"Doesn't give enough information about the new prosthesis.

"Does not take the time to correct fitting problems and to use the latest concepts and devices.

"I feel that my practitioner is not as understanding with my prosthesis since my leg was amputated at the hip. He keeps saying most people want to wear my type. I feel he could give me more support."

Overwhelmingly, respondents targeted two categories for this question:

—(22) Practitioner gives poor service and/or is unavailable

—(10+) Practitioner has poor communication skills tied with poor expertise/fitting skills.

Other failings mentioned included: supplies no information; is not up on state-of-the art advancements; no follow up; attitude problems (for example, the practitioner feeling he was superior to the patient in some way); devices and service too expensive; poor business practices; doesn't do what's best for client; poor cosmesis in devices; and doesn't give patient any choices.

QUESTION 3 (54 respondents). The thing my practitioner needs more training in is:

"Needs to know more about the newest technologies to build prostheses, like CAD-CAM, and new carbon-based materials..."

"Knowing more about advancements in the field..."

"Interpersonal skills so he can understand what is important to me.

"Understanding the need to have a prosthetic device as close as possible to match my lost leg. He shouldn't think I'm 'shallow' because I don't want people to see a 'difference.'

"Use of new components...communications skills, specifically in LISTENING.

"After explaining everything in 'medicalese', it would be very helpful (and comforting) to have a translation in English, without me having to have this dumb look on my face and glazed look in my eyes and saying, 'huh?'"

"Taking the client's suggestions and incorporating them into the prosthesis, and also in how to listen.

"Casting and fitting...making sockets."

Communication skills (21), general expertise (13), and knowledge about state-of-the-art products and components (11) were the top three responses to this question. These responses correlate closely with items targeted in question 2.

Users were also concerned with their practitioners' lack of expertise in the cosmetic aspects of their device; lack of listening to client suggestions and preferences; lack of knowledge about children's and geriatric issues; poor device comfort and excessive device weight; poor business skills and client follow-up.

It's so important to me to have a prosthesis I'll be happy with for the rest of my life, as many others would like to also, and also to have it as life-like as much as possible....

QUESTION 4 (42 respondents). I feel my practitioner doesn't understand my need for:

"Comfort and cosmesis in my device.

"Comfort and ability to walk for lengthy times without pain.

"It's so important to me to have a prosthesis I'll be happy with for the rest of my life, as many others would like to also, and also to have it as life-like as much as possible."

Again, the overwhelming majority of responses fell into two categories:

—(11) Comfortable, pain-free devices

—(10) Cosmesis in a device.

Other user needs included: explanations and information; the need for special devices (e.g., swimming legs, sports orthoses, etc.); understanding of client feelings; good, general fit; lower cost devices; improvements in mobility despite the device; service flexibility (evening hours, practitioner availability for emergencies) and the desire for state-of-the-art devices.

QUESTION 5 (98 respondents). In general, prosthetic-orthotic users need more information on:

"More information from the practitioner about options of different devices; what will be the most comfortable, not necessarily the most expensive. Also information on stump shrinkage and pain, and how long the device will last.

"Living with the loss of a limb...the use of prostheses and what is facing amputees.

"The latest prosthetics being made, because they are always improving things and I would just like to keep up to date.

"Care of the limb and prosthesis; potential health risks involved with being an amputee; prosthetic options...

"All aspects of prosthetic usage—fittings, designs, options, usage.

"New and innovative materials and devices available."

The top four information needs reported by respondents in ranked order were:

- (32) Device options
- (27) State-of-the-art advancements
- (21) Basic information on the device
- (21) Basic information on the disability and living with it

Respondents also stated that information about support groups and self-help/advocacy, costs, practitioners, books and support materials, and user rights were also a priority.

QUESTION 6 (88 respondents). I wish more research was being done on:

Responses were many and varied. The top three research targeted research items were, in ranked order:

- (14) General device design
- (12) Components, terminal devices, and feet
- (11) Device weight.

These were closely followed by:

- (7) Socket design
- (6) Medical issues (surgical alteration, pain, limb transplants)
- (6) Above-knee prosthetic designs
- (5) Comfort of device
- (3) Myoelectric technology
- (3) Sensation in artificial limbs
- (3) Cooler sockets; temperature control
- (3) Reducing device costs
- (2) Suspension of prostheses
- (2) Symes amputation issues
- (2) Upper limb needs
- (2) Durability of all devices and components.

Items mentioned only once included technology transfer of research concepts; children's devices; psychosocial issues; below knee and upper limb issues; geriatric issues; post-polio issues.

QUESTION 7 (107 respondents). When I first became a prosthetic-orthotic user, the thing I needed most was:

"A good prosthetist who knew what he was doing. A well-fitting prosthesis that helped me return to most activities I had been doing before I lost my leg. Someone to trust with my 'new life'—feeling they had done the very best they could. Support from everyone involved, from doctors to PTs.

"Support from family and lovers...It would have been nice to have been in touch with a support group, but I was not. When I asked the physician who removed my leg if there was any literature on amputations available, he told me there was none...I had a friend studying at a medical school who sent me a stack of literature he had xeroxed for me...

"A functional, comfortable leg."

As the comments show, respondents had strong feelings about their initial experiences. The three top ranking response categories for this question were:

- (36) Psychosocial needs (love, support, counselling, etc.)
- (28) Information (both general and specific)
- (18) A better fitting, more comfortable initial device.

Other responses included proper training, a good practitioner, pain relief, and financial support.

QUESTION 8 (112 respondents). Now that I'm an experienced user of prosthetic-orthotic devices, the thing I want most is:

"To make use of the latest technological advancements in designs and materials...but the big problem is skyrocketing costs and I have no insurance coverage..."

"A leg that I can use. One that feels real when I touch it. One that looks real when I look at it, and one that walks real when I walk on it."

"Comfort; being able to feel assured that needs can be met regardless of cost..."

"Function, comfort, and cosmesis. I need to have a prosthesis I can wear all day, from 7 AM to 9 PM if necessary."

The overwhelming majority of respondents to this question (38) stated that fit, cosmesis, comfort, and (18) technological advancements were the things they desired most.

Additional responses indicated that more experienced users wanted specific things such as recreational limbs or devices, state-of-the-art devices (as opposed to the conventional fittings), information resources, and "how to get more" from their device.

[People] believe we are not desirable, that we are cripples. People shy away from us like we have a disease...[Practitioners] believe that we don't care [about the device], and that we will take whatever we are told to take...

QUESTION 9 (87 respondents). The biggest misconception about prosthetic-orthotic users is:

"That we are not desirable, that we are cripples. People shy away from us like we have a disease."

"That somehow we are not normal people able to do things any normal person can do."

"That we don't care [about the device], and that we will take whatever we are told to take...that we just want to be able to do the basic activities of daily living...the belief that we appreciate any device a practitioner can give them. Ha! We expect high function, excellent fit, and respect!"

"That we cannot understand our bodies and how they work...that we don't understand what we want...that we are not knowledgeable enough to be able to tell the provider what we want and don't want...professionals think amputees are stupid."

"That anyone can use a prosthesis or orthosis without a period of training and adaptation...that the prosthesis works like a natural limb..."

These comments typify the top three categories of responses received to this question:

—(21) That users are cripples, handicapped, disabled, etc.

—(21) That users are satisfied with the usual, because users are stupid/professional contempt for the user

—(15) That users can't do many things

—(13) That the device works like the real limb. When users have a device, their problems are over.

Respondents also commented that the public seems to think that life for a person with a disability is like life for everyone else; that the disabled have "bottomless pockets" (regarding the cost of a device); that users are in constant pain; that users want pity. Many comments reflected a "social fear" of the disabled.



Respondents who felt their needs were met were active in self-advocacy and self-education about their device and their disability...

QUESTION 10 (107 respondents). I feel the prosthetic-orthotic services I have received have met/not met my needs because:

Respondents who felt their needs were met (70) gave as reasons (ranked in order of occurrence):

- (36) They have/had a good practitioner
- (26) Their device enabled them to return to normal activities
- (9) They were active in self-advocacy and self-education about their device and their disability, and/or they belonged to a support group.

Respondents who felt their needs were NOT being met (37) cited as reasons:

- (17) Their device was poor or unsatisfactory in some way
- (10) Their practitioner was lacking in expertise
- (4) They did not have the financial resources to get the "right" device
- (2) Their device was not state-of-the-art
- (3) Their problems (initial and resulting from use of a device) were not solved.

DISCUSSION. Comments received to the *Sentence Completion* questions verify the things users felt important with regards to their prosthetic-orthotic device as reported in the Part 1 report of this survey, namely:

- 1) How well the device works for user
- 2) How the device works
- 3) Comfort
- 4) Who the device looks (cosmesis)
- 5) How easy the device is to put on and take off
- 6) Weight
- 7) How long the device will last
- 8) Who will pay for the device
- 9) Who makes the device
- 10) How long it takes to make the device
- 11) How much the device costs
- 12) Geographic location of the practitioner
- 13) How much training is needed to use the device.

The *Sentence Completion* portion of the survey was also important in that it brought out the many social and personal facets of being a prosthetic-orthotic user that a mere ranking of categories (above) could not. Users felt strongly about advocacy (either having someone advocate for them or being their own advocate); their rights to make decisions and to know about choices in P&O care; their right to information; their right to quality care and quality devices, and to be treated like a human being, by both practitioners and others.

Users were supportive of research, provided they could reap its benefits and that technology transfer of research ideas was affordable.

A survey conducted by The War Amputations of Canada during the period of 1983 to 1986 (AMPUTATION, 1989) supports many of the findings of the Resource Unit survey. The War Amps reported that users were in need of information about their disability and their device; that users did not, in general, feel comfortable with their practitioner; that users are concerned with the consequences of wearing their device and their disabili-



ity; and that younger amputees were concerned with public image, cosmesis, and special use prostheses (such as those used for sports).

Another survey, conducted in Sweden (Wall, 1992), reports survey results of 400 lower limb amputees who were asked a variety of questions about their device. These users also verify what the Resource Unit survey uncovered, namely, that users are concerned with how their device works, its comfort (especially in the socket area), and the quality of the componentry used (knee mechanisms and feet were of special concern).

Users want a prosthetic-orthotic device that works, that will improve their quality of life, and that will "enable" them in all areas of living...

SUMMARY. The Survey asked the overall question: What do users want? The priorities uncovered by the survey show that users see themselves as *consumers* and *customers*: they are purchasing a product and are affected by the product. They ask normal questions about product usage and quality, and have normal expectations of the product. They are concerned about how the product is manufactured and who is manufacturing it. These products, prosthetic-orthotic devices, in fact have long-term and serious effects on their lives.

What do users want? They want a prosthetic-orthotic device that works, that will improve their quality of life, and that will "enable" them in all areas of living, not further disable them. Their questions and comments are worthy of thought. ♦

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For a copy of the questionnaire as it was disseminated, please write to the Resource Unit. Else M. Tennesen, M.S. is Project Director of the Resource Unit.



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