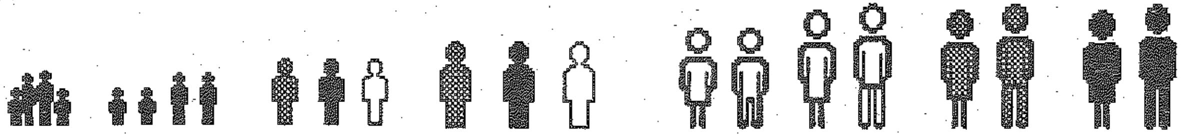
Capabilities

Communicating the Science of Prosthetics and Orthotics

VOLUME 2 NUMBER 4, JANUARY 1993



What Users Want

Part 1: Audience and Priorities

by Else M. Tennessen, 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." The purpose of this survey was to collect information that would be used internally in the Resource Unit to improve services and help guide research planning. The questionnaire was created jointly by myself and by members of our Consumer Advisory Panel. The survey consisted of four parts:

- *Ranking*—Users were asked to rank what was important to them in a prosthetic-orthotic device
- *True and False*—Users were asked to rate as true, false, or not applicable statements regarding their care by practitioners and support organizations
- *Sentence Completion*—Users were asked ten open-ended questions which solicited their opinions on practitioners, information needs, personal needs, and conceptions about prosthetic-orthotic users, and
- *Statistics*—Users were asked to supply information about their disability, type of device used, length of use, their age and sex, and their participation in a support organization.

The questionnaire was mailed to 1170 people or organizations actively involved in prosthetics and orthotics—both amputees and orthotics users were polled. Receivers of the mailing were encouraged to duplicate the questionnaire for use by their peers and other users. A return mail envelope was not provided, so returns were at the participants' discretion. In this issue of *Capabilities*, *Ranking*, *True and False*, and *Statistics* will be discussed, and results are summarized in tables on page 7 and 8.

At this writing, the *Sentence Completion* section is still being analyzed. The results of the *Sentence Completion* section and their correlation with other parts of the survey will be discussed in the April issue of *Capabilities*. Participants were, in general, candid and articulate, and completed the sentences with more information than was anticipated.

RETURNS. Counting original surveys and xeroxed duplicates, 140 questionnaires were returned to the Resource Unit. This 12% return rate is typical of mailed questionnaires where a return envelope is not provided. Surveys were received from 27 states and four countries (the USA, Brazil, Canada, and Japan.) The surveys were tallied by hand, and averaged.

There were cases where sections of some questionnaires were considered invalid (not counted). For example, for the first section, *Ranking*, the entire section was invalid if the participant did not follow the directions and complete the section as instructed. In the section, *True and False*, the entire section was invalid if it was not filled out, but if it was incompletely filled out, the answered questions were tallied. This was also true for the section, *Sentence Completion*. In the statistical section, answers were invalid if they were not completed. A general reaction to the survey as expressed by the participants is discussed at the end of this article, under the paragraph, *Participant Response*.

Continued on Page 5

In This Issue

NORTHWESTERN UNIVERSITY ◆ Rehabilitation Engineering Program ◆ Prosthetics Research Laboratory ◆ Resource Unit for Information and Education

Consumer View

In the Eye of the Beholder

by Lorna Renooy

The concept of beauty is as old as human history. Imperfections or deviations from the accepted standard of attractiveness have long been viewed as inferior characteristics. Our present society continues to value a certain ideal of physical beauty, so much so that those who have any type of disability may experience the pain of isolation and rejection. Whether affected by a congenital defect, or having acquired a disfigurement or disability through trauma or disease, coping in a society which is obsessed with physical perfection presents countless challenges. For many, the difficulties in overcoming the stigma attached to looking different is enormous.

While listening to fairy tales at a very early age we are taught that what is beautiful is good, what is unattractive is evil and undesirable. As we mature, we are inundated by messages of how we should look, and what we should strive for if we fall short of the accepted ideal. Nearly every form of media and advertising tells us that any defect is socially unacceptable and should be hidden or corrected. While our society pays a great deal of lip service to judging a person by inner worth, the sobering reality is that the stereotypes which we are taught, and the images of perfection that surround us are not readily forgotten or overcome.

Taking public transit, shopping, attending school, walking on the street, any activity in which a physically challenged person is in the "public eye," can be fraught with difficulties that range from stares, whispers, rude comments, derisive laughter or overt ridicule. For a person with a disability, confrontations with a judgmental and unaccepting society are often inevitable, depending upon the severity of the disability. Others' negative reactions, based solely on appearance, are intrusive and are bound to weaken one's self-esteem and self-confidence. Such incidents can have a lasting and significant effect. A physical challenge can be a *social disability* in that it can negatively impact on an individual's ability to be part of the community, to develop meaningful social relationships or to reach one's full potential.

However, visible physical differences can be, and are, perceived in many different ways. What is considered physically attractive, and that which is acceptable, is highly personal. One person's idea of what is desirable may differ greatly from another's. The underlying issue may be the question of what true "beauty" is. Regardless of the outside package, someone who has developed positive personality traits and strong social skills is an appealing person to know. Appreciation of the person in his or her entirety IS appreciating real beauty.

We are all different in some way. The challenge to people who have physical differences is to believe in themselves, and to promote the view that "different" need not be a negative attribute. In this sense, we can create our own reality. Beauty and what is attractive are personal issues, and should not be dictated to us by advertisers and other forms of media. Working to change attitudes which have been built over centuries is a process which takes time. The barriers to acceptance will continue to exist as long as the visible differences are seen first, and the person last. Education and awareness are the tools to building a bridge of understanding.◆

Ms. Renooy is Editor of AboutFace, *a newsletter concerned with facial disfigurement. AboutFace is based in Toronto, Ontario Canada. This article was previously published in the November/December 1992 issue of* AboutFace. *We are pleased to reprint this very relevant consumer view.*

S.O.A.

Accessibility and the Amputee

by Bill Lintz

Accessibility, ADA, ramps, curb cuts, tactile markings, TTY, TTD—these are the new "buzz words" in our society. Accessibility is a big subject. There are almost as many applications and solutions as there are people with disabilities in America. The unique problems of one person may be solved in one way, yet that same solution may create a problem for another person with a different disability. Does this mean we shouldn't try to solve disability access problems? Certainly not. What we have to recognize is how one solution affects another.

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For example, most access designs over the past 30 years were engineered for those with severe mobility impairments, most notably those in wheelchairs. Before the mid-70s, people in wheelchairs had little access to anything. They could not get up curbs and steps into buildings, they could not get into doors, and they could not get into rooms. Restrooms were impossible to get into and use. Current access design focuses on these problems.

While progress has been made on the one hand, the needs of some groups, most notably prosthetic and orthotic users, have not been considered. Also ignored, to some extent, are some of the needs specific to people with visual impairments, or the physically infirm.

Let me review just three design features which for some of us are NOT access helps:

RAMPS. Steps are a problem to those with mobility impairments and the ramp, for example, while giving much needed mobility and access to the wheelchair user, creates certain problems for other disabilities. Ramps can make it hard for someone with balance problems to circumvent those facilities. Ramps take more effort to negotiate than stairs for some people. Prosthetic users, particularly above-knee amputees, have a great deal of trouble with ramps. It is extremely hard for many above knee amputees to go up ramps, and dangerous to try to go down. The length of a ramp often does not give someone with heart or breathing problems sufficient places to rest.

CURB CUTS. These are some of the most misunderstood and poorly designed features you'll see. There is no uniformity in design, not only from city to city and state to state, but even within a given city. For example, Columbus, Ohio has at least 15 different types of curb cuts. Some are dangerous and also create access problems for those with visual impairments, for prosthetic-orthotic users, and for those with balance problems. Some even tip over the wheelchair users they were supposed to accommodate.

Sadly enough, many in the disability community do not even understand the problems or solutions themselves. For example, in good faith a city came to leaders of several organizations for the visually impaired for help in curb cut design and marking. They approved a city-presented design that although "tactile", gave no tactile directions. This curb cut can and does send visually impaired persons straight into the middle of intersections! It has no visual shading differentiating the surrounding sidewalk, holds water which freezes in winter, and even non-disabled people trip and fall over them in good weather. It is extremely difficult for an amputee or for someone with multiple sclerosis to negotiate these curb cuts. No one has ever asked the amputee community how to make curb cuts and ramps more accommodating to them.

TELEPHONES. Lowered phones, while being more accommodating to the wheelchair user, were not designed for easy use for an amputee or for anyone who might have problems bending down. The phones are hard to see, and harder still to use because of the unnatural angle one has to be in to use them. When several phones are available—some low, some at regular height—that's great. Too often, however, we are seeing ALL phones lowered in a facility—another good idea improperly executed.

Some of you reading this newsletter are among the movers and shakers in the disability community. YOU need to get involved, informed, and knowledgeable about the needs of your own constituency. Become an expert on access for your group. YOU need to be available to government, business, civic committees, boards and service organizations that can and do work with access designers. Get as broad-based a cross-section of the disability community as possible organized so that you can promote proper access design and implementation. If you have a Center for Independent Living (CIL) in your community, support it, for this can prove to be an excellent focus organization for these activities. Strive for access for everyone, young and old. Only in this way can we all become truly independent.◆

Bill Lintz is a member of Northwestern University's Rehabilitation Engineering Program's Consumer Advisory Panel. Mr. Lintz is President of COAST, Inc., the Central Ohio Amputee Support Team, an amputee support group. He served as the Accessible Housing Analyst for MOBILE (Mid-Ohio Board for an Independent Living Environment). Currently, Mr. Lintz is the Executive Director of the Knox and Ashland County (Ohio) units of the American Cancer Society.

Review

AMPUTATION

The Journal of the War Amputations of Canada

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AMPUTATION is a veritable potpourri of state-of-the-art information for the amputee and the prosthetics profession. Published every two years, and distributed

Continued on back page

(Ed. note: Occasionally, this newsletter will print a piece relevant to advocacy under a column so titled. The views here are those of the authors.)

Peace on Earth

by Linda Ratto, M.Ed.

Long after the last Christmas decoration is snug it its storage box, is the idea of "Peace on Earth" as out of reach?

I attend rehabilitation conferences often through my work and find one disheartening element at each one: discrimination. There is a feeling I have from comments by conference attendees and professionals that people are still not accepting people as people first.

Within the disabled community, we must accept the fact that although I may not have had the same physical condition as you, we are more the same than we are different. Let me give you an example: I was engaged in a conversation with a person who had experienced head injury. I have not. I am an amputee, having had two mastectomies. We shared our past briefly. But then I sensed a struggle, a friction between us. I was being told, in subtle ways as well as with specific wording, that although I must have had a difficult time, I could never understand what it was like for the head injured.

I can take this conversation one of two ways. I might proclaim that I will never in my life understand what any other person is going through who has NOT had my experience (two mastectomies and six months of chemo, all while my children were all under five years old), and I will never understand what others feel or go through because I'm not them...OR...

I may decide that the human experience is filled with periods of grief and tragedy. I can decide to relate to my fellow human beings as people with trials which are similar to mine. I can seek to share experiences which, on a universal level, are very common to other people's hardships. They just call it something other than amputation from cancer—like heart attach, auto accident, congenital anomaly, divorce, death, or trauma by any other name.

My first child was born with only one hand. I had her tested. I felt alienated, alone and very depressed. But I had a child to raise, a person to help mold into a happy, thriving citizen. I chose to work with what we were blessed with, even if it meant sharing my sadness. We were ALIVE!

My life's work is focused on pointing out to others that we all have so much in common. We CAN relate to one another! Persons experiencing head injury have had extreme physical and mental violations and impairments happen to their bodies. I have, too. Different impairments—same feelings. It just so happens that we have been placed on this earth with millions of other human beings. Why are there so many of us, if not to learn and share and find value in each other?

It would give our disabled community a tremendous boost if we refused *to discriminate among ourselves...*

It would give our disabled community a tremendous 1993 boost if we REFUSED to discriminate among ourselves. We are people with challenges. All people have challenges. If we still feel angry about it all, then call it anger, call it grief. But let's call our community members people who understand grief and who are seeking positive ways to cope and live well. United in this effort, our society will learn how to cope well, too. Global acceptance will come quicker as a result.◆

Linda Ratto is a writer and rehabilitation consultant specializing in trauma, amputation, and breast cancer. She is a member of Northwestern University's Rehabilitation Engineering Program's Consumer Advisory Panel. She lives in Atlanta, Georgia. This article © 1993, Linda Lee Ratto, M. Ed. Used with permission.

What Users Want, from page 1

PARTICIPANT PROFILE. Who answered the questionnaire? The typical respondent was male, 49 years of age, a lower-limb amputee with below-knee prosthesis, a P&O user for 11.6 years, probably belonging to a support group. There were 121 prosthesis users and 19 orthosis users in total. Of the prosthesis users, most were lower limb amputees. A small group (27) were upper limb amputees, combination amputees (bilateral or other), or presently wore no prosthesis. All the orthosis users wore lower limb orthotics. The low number of orthosis-user responses can be accounted for by the general bias of the mailing/dissemination, which was to amputee clients and organizations.

Of those who responded, most were male. The age range of all respondents was 19 months (a questionnaire completed by a parent, as were most of the children's) to 79 years. The range of length of device use was 6 months to 62 years. With regards to support organizations, there was an even chance of the respondent belonging to one or not. This was an interesting finding, considering that at least 200 of the original 1100 questionnaires were mailed to support groups.

RANKING. Participants were asked the question, "When shopping for a device, what things are important to you?" Thirteen items were presented, and the user was asked to rank these in order of importance, giving the number 1 to the most important item and the number 13 to the least important item. If the section was incorrectly or incompletely filled out, the entire section was not tallied. After tallying, the thirteen items fell into three distinct categories of importance as follows (and are shown in order of tally):

MOST IMPORTANT

- How well the device works for me (functionality/replace lost function/etc.)
- How the device works (components, mechanical complexity) *tied with*
- How comfortable the device is
- How the device looks (cosmesis)

IMPORTANT

- How easy the device is to put on and take off *tied with*
- How much the device weighs
- How long it will last (time needed between repairs). *This item also tied with weight and who will pay for the device.*

LEAST IMPORTANT

- Who will pay for the device (insurance or self)
- Who makes the device (competence of practitioner/facility)
- How long it takes to make the device
- How much the device costs
- Geographic location of practitioner/facility *tied with*
- How much training the user will need to use the device effectively .

Users were very interested in functionality and componentry as exemplified in their comments. Comfort and cosmesis were also high priorities. Participant comments verify these priorities. Interest in information on state-of-the-art advancements in device development and their availability to the user was frequently mentioned.

TRUE AND FALSE. Seven statements were presented to participants. The response choices to the statements were true, false, or not applicable. If the section was incompletely filled out, only answered statements were tallied. Each statement will be discussed separately.

1) Participants were asked, "My physician has good follow-up and stays in touch." An even number of respondents answered true or false to this statement. Sixteen percent of respondents replied "not applicable" to this statement. One may infer that this means they either do not have contact with their physician, or this item is not important to them.

2) Participants were asked, "My prosthetist/orthotist follows up on my progress regularly." Fifty-seven percent of respondents considered this statement true. Thirty-four percent considered this statement false, and the remainder considered the statement not applicable. This may mean that no follow up occurs or follow up is not important to the respondent.

3) Participants were asked, "My rehabilitation professional follows up on my progress regularly." Seventy-four percent of respondents considered this statement false or not applicable. This was a surprising finding since most post-surgical/illness contact is with a rehab professional (physical therapist, occupational therapist, etc.).This question may also have been interpreted to mean *after* a course of therapy was completed, which can also explain the results.

Continued on Page 6

What Users Want, from page 5

4) Participants were asked, "Initially, my physician gave me as many options/choices as possible concerning surgery/illness outcomes, etc." Forty-two percent of respondents said this was true. Thirty-six percent considered this statement false. The remainder chose "not applicable" as their response to this statement. Some respondents explained that they chose "not applicable" because their surgery and/or illness was a result of trauma or other causes where choices were not possible.

5) Participants were asked, "Following my surgery/illness, I was given plenty of information about my disability, prosthetics/orthotics, and support organizations." Fifty-three percent of respondents considered this statement false. Fourteen percent considered this statement "not applicable." In general, comments from respondents show that getting information, ANY information, is a high priority. Although respondents stated that they received pre-surgery information, they did not receive information about post-surgical/illness outcomes.

The last two statements related to support groups or organizations. For both statements, the majority of responses were evenly divided between "true" and "not applicable." Of all returned surveys, respondents demonstrated that half belonged to support groups and half did not (which may account for the "not applicable" responses.)

6) Participants were asked, "My support organization meets my needs." Taking into account only true (59) and false (17) responses, the overwhelming majority felt this statement was true.

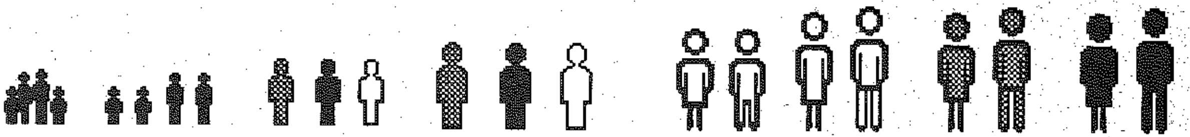
7) Participants were asked, "My support organization has a peer visitation program." Again taking into account only true (55) and false (18) responses, the overwhelming majority felt this statement was true.

STATISTICS. Some statistical information has already been discussed in the section, *Participant Profile*, above. All respondents could describe their level of amputation or reason for orthosis use. Some participants chose not to share their age or sex. Of interest is the general response to the question, "What kind of prosthesis/orthosis do you have now?" The aim of this question was to see whether respondents knew what kind of device they had, its componentry, and general use. Most DID NOT (not even to the extent of saying "I have a BK prosthesis," or "I have an AFO"), however; a small number of respondents knew EXACTLY what they had, down to construction details, manufacturers' names, components, and component capabilities. The majority of respondents who did not know or who could not answer this question may reflect those who were not receiving information or understanding the information they did get.

PARTICIPANT RESPONSE TO SURVEY CONSTRUCTION. Comments from respondents showed that the first section, *Ranking*, was unpopular and difficult to complete. Future ranking surveys may need to reduce the number of items ranked, or explain the ranking process more clearly. For true and false, the large number of "not applicable" responses may mean that the statements were not understood or not applicable or important to this audience. The statistical section, which collected basic information, was not commented on. In general, respondents considered the *Sentence Completion* portion of the survey as the most important. This free-form venue for feedback was popular and most respondents did not mind completing ten statements. Some respondents complained that the survey was too long and took too long to complete. The Resource Unit tried to anticipate this difficulty by disseminating the questionnaires at least one month and a half before their return was expected.

PART 1 SUMMARY. Users were explicit about their priorities in shopping for a prosthetic-orthotic device and had strong opinions about the follow-up and information they received from their health professionals.✦

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



WHAT USERS WANT
PART 1 SUMMARY
TABLE I

SURVEYS	
Disseminated	1170
Returned	140
Geographical Area	27 states, 4 countries
RESPONDENTS	
Total	140
Prosthesis-Users	121
Upper Limb	14
Lower Limb	94
Other (bilateral, combination, etc.)	13
Orthosis-Users	19
Lower Limb	ALL
LENGTH OF USE	
Range	6 months to 62 years
Average	11.6 years
AGE	
Range	19 months to 79 years
Average	49.1 years
SEX	
Male Respondents	85
Female Respondents	53
SUPPORT GROUP MEMBERSHIP	
Yes	70
No	67

RANKING (in tallied order)

1) How well the device works for user
2) How the device works
3) Comfort
4) How the device looks (cosmesis)
5) How easy it is to put on and 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 practitioner
13) How much training needed to use device

See Table II, page 8, for TRUE AND FALSE.

REVIEW, from page 3

free, it offers articles, comments, and data which The War Amputations of Canada has collected in its continuing search for the latest in technology and prosthetic innovation. Often, initial information about a new prosthetic breakthrough is first published in AMPUTATION.

A typical issue will include sections on:

- Artifical Arms and Hands—featuring articles on caring for your prosthesis, the latest in terminal devices, and children's specialties
- Artificial Legs and Feet—featuring articles on modular prostheses, components, and prosthetic feet
- Sockets and Support Systems—featuring the latest in socket technology and socket manufacturers
- Recreational Limbs—featuring specialized arm and leg prostheses for fishing, swimming, scuba diving, beach walking, bicycling, playing musical instruments, and other sports and pastimes
- Aids and Devices—featuring socks, aids, lotions, and other amputee needs
- Miscellaneous Articles and Comments—a forum for questions and answers about amputation and prosthesis use.

Each issue also contains a helpful glossary. The magazine is attractive, easy to read, and uses photographs and illustrations liberally. The magazine reflects well on the goals and priorities of The War Amputations of Canada—which although is based in Canada, has something to say to all amputees internationally.

The War Amputations of Canada, a not-for-profit organization, offers social and financial specialized assistance to amputees of all ages. The War Amps' chief philosophy is that of "amputees helping amputees," and it sponsors programs, seminars and peer support to back this philosophy. The next issue of AMPUTATION will appear in the summer of 1993.◆

WHAT USERS WANT
PART 1 SUMMARY
TABLE II

TRUE AND FALSE

Statement	# Respondents	T	F	N/A
1)	135	58	55	22
2)	137	78	47	12
3)	136	36	52	48
4)	137	58	49	30
5)	135	44	72	19
6)	133	59	17	57
7)	135	55	18	60

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