Consumer involvement, a thorough assessment process, appropriate technology, outcome measures, follow-up programs... These are just a few of the pieces that form the intricate puzzle known as quality assurance. How well do they fit together in the rehab field?

By Kimberly Pfaff, TeamRehab Report

Marka Hayes, 32, of Rockville, Md., was born with spastic cerebral palsy. She performs most tasks independently, and uses a power wheelchair to get to and from her office. But her first experiences with the chair were less than ideal, because upon receiving it she discovered it had a fixed recline that was significant enough to render it uncomfortable and awkward for her to use.

“The seat sloped back like a recliner,” she recalls. “It increased my tone so that my legs just shot straight out all the time. I couldn’t pull onto the bus easily, couldn’t reach doors.”

Throughout the assessment process, no member of Hayes’ rehab team informed her of the wheelchair’s sloping position. “I had no idea the chair had a fixed recline,” she says. “It wasn’t explained to me at all. I would have thought any chair I would have bought would be at 90 degrees. It didn’t occur to me that the chair would be at a
fixed degree sloping backwards.”

After contacting her therapist and supplier, Hayes was told the $8,000 chair could not be adjusted from its set angle. She used it for several months before resorting to the mechanical inclinations of her then-future husband, who cut the chair at the base, repositioned it upright at a 90-degree angle, and welded it together.

Although Hayes uses the chair, she says that seatingwise it’s still not right. She uses a manual chair at work and at home.

Manufacturers who spoke with TeamRehab Report noted that home tinkering such as this can have serious consequences for consumers, in many cases voiding some or even all of a product’s warranty, depending on the extent of the work done.

Incidents like this are one reason why quality assurance (QA) has become such a hot topic in the rehab field. Delivering quality service and technology is essential for an industry that seeks to improve the lives of disabled individuals.

“We have to develop a method by which people with disabilities can reliably receive appropriate technology,” says Gerry Warren, president, C. Gerald Warren & Assocs., Seattle, Wash. “We have to have a service delivery system that operates with a good QA program, to make that happen.”

According to Hayes, not one of her rehab service experiences has ever been fully satisfactory. “Nothing I ever get is totally thought out,” she says, adding that the equipment she’s received has ranged from being “almost totally nonfunctional to something I could get by with.”

Lengthy service delays are another constant battle, she notes. “My pet peeve is putting the chair in the shop for routine maintenance, and closed. After contacting her therapist and supplier, Hayes was told the

As a disabled person working in the rehab field, he believes he brings a valuable perspective.

“I get a lot of hands-on experience with people coming in to be reassessed for chairs, and a lot of times I’ll suggest alternatives to them, and ways to make a chair more comfortable for them,” Broyles says. “From that aspect, having someone with a knowledge of sitting in the chair every day is helpful.”

MAKING PROGRESS

By contrast, the parents of Victor Padilla Jr., a 4-year-old from Whittier, Calif., have had only positive rehab experiences.

Victor was born with arthrogryposis multiplex congenita, an orthopedic disability that causes multiple joint deformities and muscle weakness. As a result, he is unable to walk, roll or sit up by himself, although he does have good trunk control when sitting upright. He also has good use of his head, and is at the right cognitive level for his age.

Because he was very involved medically at birth, Victor had a tracheotomy tube inserted when he was just a few weeks old. He was put on a respirator shortly thereafter. At age two, his trache opening was reassessed for chairs, and a lot of times I’ll suggest alternatives to

During the first half of his life, Victor underwent multiple surgeries for medical and orthopedic reasons. Doctors cautioned the Padillas that the most they might expect for their son was that he would be able to move his head independently.

But with the help of a cohesive rehab team, Victor’s prognosis became much brighter. Thanks to an innovative pediatric powered mobility program at his rehab center, Victor was evaluated for powered mobility at 34 months. Today, he attends a regular preschool and uses an Everest & Jennings Hot Wheels power chair. Its center-mount proportioned joystick control was designed with decreased resistance in the joystick to accommodate Victor’s weak muscles.

The Padillas hope that, perhaps with additional surgery and rehab, Victor might one day walk. They have only praise for the work his rehab team has done.

“Victor’s been progressing with all the help from his teachers and the occupational thera-
Cultivating Quality

They are grateful that their son, whom doctors first predicted might only be able to move his head, has come so far so fast. Says Padilla, “For us, it’s been like winning the lottery.”

DEFINING QUALITY

Quality assurance incorporates many varied elements, including consumer input, properly trained professionals, a team approach, and outcome measures. Its aim is to deliver suitable technology and ensure consumer satisfaction. A QA program, rehab professionals told TeamRehab Report, should ideally include the following components:

- A thorough assessment process
- Qualified professionals
- Consumer involvement
- Appropriate technology
- Timely service delivery
- A working relationship with the payer source
- Outcome measures that accurately reflect the result of supplying assistive technology

A consumer-responsive complaint procedure

One of the first steps toward making QA a reality, professionals say, is bringing different disciplines together as a rehab team for the client assessment. “If you have a team approach, you then have different perspectives and a check and balance system,” says Cynthia Cress, Ph.D., C.C.C.-S.L.P., Meyer Rehabilitation Institute, Omaha, Neb. “You can concentrate on the areas you know best, and communicate together for an overall perspective.”

Which professionals are qualified to be a member of the team? What particular skills should they possess? These are questions RESNA is trying to answer, as the organization works on guidelines for assistive technology practitioners (see sidebar). The association is trying to determine which kinds of knowledge and skills should be common to all providers of assistive technology, and which are specific to each discipline.

Identifying qualified professionals through credentialing and certification has become an important issue. Says Warren, “Credentialing allows people to identify themselves as qualified providers, and it allows the consumer-and the payer-to be able to identify who is qualified.”

One example of this move toward credentialing is the National Registry of Rehabilitation Technology Suppliers (NRRTS), chaired by Adrienne Bergen, P.T., Dynamic Medical, Westbury, N.Y. The organization seeks to help clinicians, consumers, and third-party payers identify qualified suppliers, as well as ensure the provision of quality ser-

The Last Puzzle Piece: Client Follow-up

As rehab professionals, we frequently put all our energies into providing an effective assistive technology intervention for a client, and are then left to wonder whether the device-user match was successful. A client follow-up program, however, can answer this question and provide valuable data on why certain solutions did and didn’t work.

In 1988, the Research Engineering Center (REC) at Lucile Salter Packard Children’s Hospital at Stanford, Calif., (LSPCH) conducted a study of consumer opinions regarding assistive technology. As part of an ongoing study of consumer satisfaction, the overall goal was to improve the transfer of rehabilitation technology from the evaluation and delivery stage to functional use by the disabled consumer.

METHODOLOGY

The study was conducted in three phases.

In the pilot phase, we followed 60 clients for one year. The outcome measures selected upon the basis of this study were:

- function with device;
- use (hours per day);
- comfort;
- safety; and
- need for and number of repairs.

The second phase involved four other centers which agreed to a seven-month study, and performed

- initial evaluation, without device or with “old” device;
- evaluation at delivery with new device;
- phone calls at one, three and six months post delivery for an “intervention” group, and no such calls for a “control” group; and
- evaluation at seven months post delivery for both groups (94 percent of the devices were still in use at that time).

The total population studied was 163 clients. They received the following devices:

- 73 custom seating systems
- 24 ADL bath benches
- 20 communication devices
- 14 power wheelchairs
- 13 unilateral below-knee prostheses
- 10 TLSOs (thoraco-lumbar-sacral orthoses)
- 9 standard seating systems

The final phase of our study involved a phone call at two years post delivery to the 60 clients in the original LSPCH-REC
technology intervention being done by people who don’t completely understand what they’re doing.” Warren relates. “They either need to be sure they understand what’s going on or refer to other people, who can assure that appropriate services are provided.”

“When a client is having a loss of function, or developing a pathology such as pressure sores or scoliosis...then we advise they should be seen by a medical professional, not just a supplier,” notes Janice Hunt, M.S., P.T., Samaritan Rehabilitation Institute, Phoenix, Ariz.

**CLIENT INPUT**

Also included in the rehab team, of course, should be the client and any others who will be affected by the proposed intervention—family members, caregivers, teachers, employers. Once the team is assembled, they can identify the client’s needs and goals, which will later become outcome measures.

The problem that occurs, professionals say, is that no clear guidelines for the assessment process currently exist, although RESNA is working to change that.

“The issue for the field is coming up with guidelines for professionals who may not be aware of all the kinds of issues to raise in a technical assessment,” says Cress.

“There’s no consistency of methodology in the way assessments are done by clinicians, and standards for who will accept what level of responsibility,” notes Jeff Offner, president of Rehabco, Bronx, N.Y., which provides rehabilitation technology services.

To assure proper and consistent use of the equipment, it’s important to be certain that all the people who will be closely interacting with the client are committed to and comfortable with the chosen equipment.

“Sometimes we start with good goals, but we forget to incorporate all those other people,” says Hunt. “So the child goes back to school, and if the teacher doesn’t like the way the system works, he or she might not use it. Now this wonderful therapeutic positioning won’t be there for the child at school, because the teacher has other goals.”

“That’s the element of QA we tend to leave out,” Cress says. “We forget attitudes and preferences as an equal factor in QA.”

Rehab professionals agree that forcing a client to use equipment they don’t want, but which may be more therapeutically beneficial, is pointless. Says Hunt, “If they don’t want it,
they won’t use it. And if they do want something, they’ll figure out a way to get it.”

Hunt relates that she once dealt with a young man with very severe athetoid cerebral palsy, who required an aggressive seating system to position him so that he could use his hands to hit an augmentative communication switch. Although he lived in a group home and the staff there was pleased with the system, his mother took a strong dislike to it.

“Because his mother was not involved in the assessment process due to illness, she never bought into the aggressive seating system,” she recalls. “After two years of fussing with her, the seating system was practically abandoned because she couldn’t stand the way it tied him down. The moral of the story: Make sure you have all the caregivers buy into the intervention.”

The key to achieving agreement, professionals say, is through constant communication—both written and spoken—before, during and after the assessment process. Also, including equipment trials as part of the assessment can help alleviate any unwanted surprises, such as the reclining back incident that Hayes encountered.

Even in instances when an assessment has been successful and the appropriate technology selected, there are other elements that can cause the intervention to backfire. “I can do the assessment, and justify it, but sometimes it falls apart [because of other factors],” says Joy Hammel, M.Ed., O.T.R., Palo Alto Veterans Hospital, Palo Alto, Calif.

Proper installation of all the technological components, she notes, is critical. Equally important is training people how to use the equipment—that includes the user as well as any attendants, teachers, employers, or others who are closely involved.

Sometimes a consumer or their family has unrealistic expectations, and so feels the rehab team has failed in its service delivery efforts when those expectations are not met.

“Often, equipment is blamed rather than the patient’s condition,” says Offner of Rehabco. “A parent thinks a product is going to cure their child and make them normal. Obviously, the supplier is the extension of that equipment.”

“It’s important to listen to what is not said out loud—the hidden agenda of client, caregiver, educator, etc., can sabotage the process,” notes Dynamic Medical’s Bergen.

“We’ve functioned in a medical world for so long, it’s hard for us to say that consumers with disabilities should be active members of the planning team.”

-Joy Hammel

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However, as Marka Hayes’ story illustrates, consumer involvement is one area that still needs improvement. “We’ve functioned in a medical world for so long, it’s hard for us to say that consumers with disabilities should be active members of the planning team,” says Hammel.

“So often, even if we’re trying to relate the consumer perspective, it’s rehab professional-directed, rather than consumer-directed,” notes Cress. “For QA in the long run, as much initiative needs to be consumer-directed as well as professional-directed.”

Hayes recalls an instance where she waited one year for insurance to approve a manual wheelchair, and when it came she could not use it right away because it wasn’t fully assembled. “It was delivered in such a manner that it was not usable,” she says. “No one adjusted it, they just dropped it off. The wheels were on, but the chair did not roll with me in it. I had to wait for my therapist to come and fix it for me. These were things that I was physically incapable of doing myself.”

Says Hayes, that experience not only inconvenienced her, but once again put her, as the disabled consumer, in a passive, dependent position. “There you are, all excited, thinking freedom’s finally here, and you’ve still got to wait for someone to help you,” she says.

Rehab professionals agree that the current system often renders the consumer vulnerable. Changes must be made, they say, to promote consumer independence. “We’ve created this nice cycle of dependency, where when things fall apart [the consumer] calls the pro-

The Last Puzzle Piece: Client Follow-up

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pilot study to assess longer-term outcome. In our original study, at six months 92 percent of devices were in use, and at 12 months, 74 percent of the clients contacted said their device was still being used.

**FINDINGS**

At 24 months of 60 clients, 19 were lost to the study: four were deceased, 10 were unable to be located and five declined to be interviewed. Of the 41 remaining clients, 66 percent were still using their devices, and 34 percent were not. (An assumption was made that the 15 clients who did not provide information had the same level of use. Therefore, the chart shows a 60 percent use for 56 clients, since four of the original 60 were deceased.)

The following reasons were given for nonuse: four received new devices; four “outgrew” their devices because their condition improved; five discontinued use by physician recommendation (all were TLSO wearers); and in one client, surgery changed the need for the device. We were therefore able to show that the 14 clients not using their devices at two years post delivery had reasonable explanations for nonuse or replacement.

The data obtained indicated that it was possible to document the outcome measures listed previously for a wide variety of assistive devices.

<table>
<thead>
<tr>
<th>Time From Delivery</th>
<th>Percentage of Use</th>
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<tr>
<td>Day 1</td>
<td>100%</td>
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<tr>
<td>6 mos</td>
<td>95%</td>
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<tr>
<td>12 mos</td>
<td>90%</td>
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<td>24 mos</td>
<td>85%</td>
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As a quality assurance tool, a follow-up program monitors service systems, client satisfaction, staff performance and device operation. This information allows change of existing delivery methods based upon the findings.

Follow-up programs will become increasingly important as our industry continues to focus on the following issues:

- Outcome measures in relation to costs;
- Accreditation, licensure, certification issues for assistive device providers; and
- Consumer interest in, and demand for, quality performance of devices.

The five centers involved in our study have proved that it is possible to implement such a follow-up system to the benefit of all concerned.

Acknowledgement

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The findings from this study were obtained through clinical evaluations and client feedback. These data collection instruments have been compiled in an easy-to-use manual, A Quality Improvement Program For Providers Who Deliver Assistive Technology, which is available in hard copy form and on a Macintosh floppy disk for a nominal fee. For additional information, contact the LSPCH-REC.
fessional,” Hammel relates. “I’d like to see consumers knowing how to ask for help. They could go to the independent living center and use their bulletin board, call a consumer hotline, use ABLEDATA, or call the vendor and troubleshoot.”

“One of the biggest challenges is empowering the user or family to say that they are responsible to follow up on their own care,” says Offner of RehabCo. “Once they get into the system, they become helpless and expect everyone to help them. They need to [follow up] because of reduced reimbursements. Vendors can’t do it and stay in business and do good work.”

The final component of QA is a thorough follow-up system to determine whether team recommendations have been met, whether equipment is being properly used or needs repair, and whether the consumer’s physical capabilities have altered over time.

“We have to keep track of [clients] once they’re out in the community,” says Hammel. “Frequently, they have technology that’s five years old, and in this field that’s like a dinosaur.”

“People change and their equipment needs to change with them,” says Hunt. “Things we thought would work, sometimes don’t work so well in a different environment. The equipment needs to be tweaked, adjusted, modified.

“Does it usually happen? No. For one simple reason-funding. It is rare that a funding agency will pay for that follow-up.”

As for consumer Marka Hayes, she has turned her negative rehab experiences into positives. She is presently working in the disability field as a grant support specialist in the public affairs office of the National Easter Seal Society in Washington, D.C., and she is also a member of the NRRTS advisory board.

With her MBA degree now behind her, she plans to open shop as a rehab technology supplier. She believes her personal experience on the front lines as a disabled consumer will give her more insight into what disabled people find lacking in the system. “I’d like to make the small modifications that make all the difference,” she says.