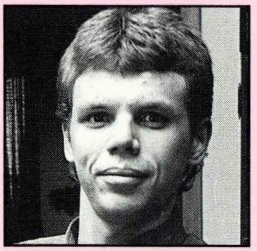
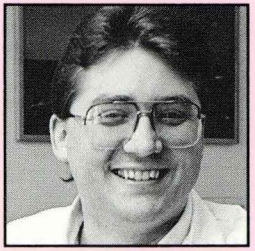
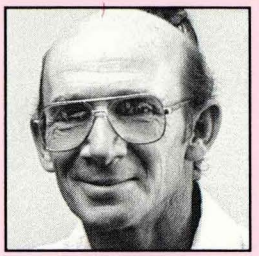
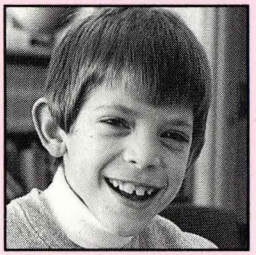
FINDING A WAY

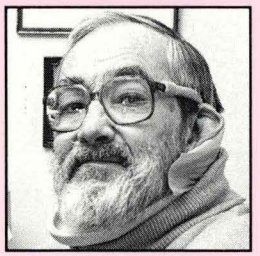




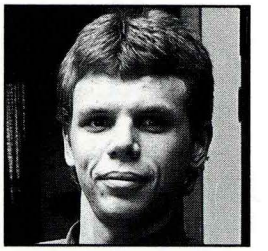


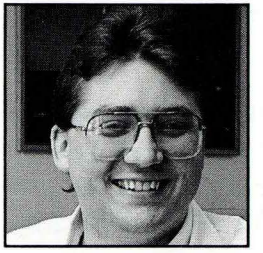
Iowans, Independence, and Assistive Technology

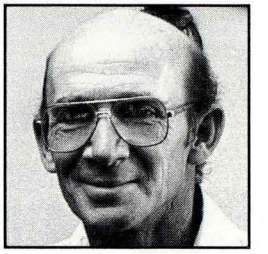


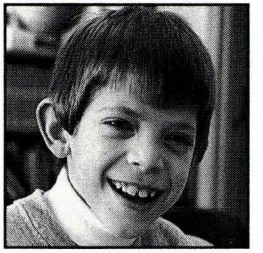


FINDING A WAY









Iowans, Independence, and Assistive Technology

Nancy Witt
Arthur Jackson

Table of Contents

Introduction

Necessity is the Mother of Invention..... **1**
Dan and Laura Becker

Involvement—The Key to Living..... **5**
Daniel Clark

Finding the Right Tools for the Job..... **9**
David Gosch

A Model for What Can Happen..... **13**
Tom Linde

Growing Up in the Real World..... **17**
Justin Novak

Getting Along Very Well..... **21**
Johanna Van Houten

Conclusion..... **25**

Introduction

When you first hear the term *assistive technology*, you might think of the Saturday morning cartoon about a space age family, *The Jetsons*, surrounded by a weird and wonderful variety of amazing gadgetry. But assistive technology is actually something quite different. The term includes all of the tools and services—high tech and low tech—that people with disabilities use to make their lives more independent and fulfilling.

This issue—quality of life—is an important issue in Iowa. We pride ourselves on our commitment to our families and our communities. As Iowans, we care about Iowans. In the lives of the Iowans whose stories are told on the following pages, assistive technology plays an important role. It is used at home, on the job, and in the community.

On these pages, you will meet:

- a pair of Merrill, Iowa inventors who create new technology;
- a Des Moines occupational therapy associate;
- an 18-year-old future farmer from Schleswig;
- a highly energetic clinical psychologist from Knoxville;
- a busy third grader from Atkins; and
- an active 78-year-old retiree from Mason City.

For each of these Iowans, assistive technology is not a high tech hope for the future, but a present reality—the tools they use, every day, to improve their quality of life.

Each will tell you that getting the right tools for the job—the appropriate assistive technology to meet their needs—is neither cheap nor easy. But each will also tell you that assistive technology is making an enormous difference in their lives.

Nancy L. Witt

Nancy Witt
Reinbeck, Iowa

Arthur Jackson

Arthur Jackson
Cedar Rapids, Iowa

Dan & Laura Becker

Dan and **Laura Becker** of Merrill, Iowa, have proven the truth of the old cliche, "necessity is the mother of invention."

Both Beckers have physical disabilities. A car accident two years ago left Laura with brain and spinal cord injuries. Dan has chronic muscle disease and a back injury. But the Beckers haven't let these difficulties keep them from using their imagination and Dan's mechanical abilities to create assistive devices for Laura and for others with disabilities.

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...the Beckers use their imagination and Dan's mechanical abilities to create assistive devices...

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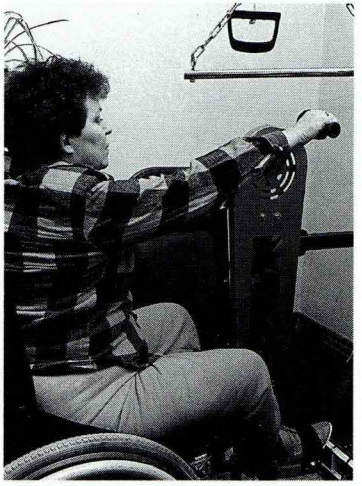
"Most of what I use has been adapted or created by Dan... You usually don't know what you need until you need it."

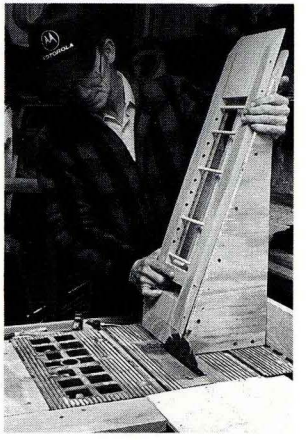
The Beckers' ingenuity and willingness to experiment mean that Laura Becker is able to live a more independent life in their rural Iowa home.

"Most of what I use has been adapted or created by Dan," Laura says. "You usually don't know what you need until you need it." To work in the kitchen, Laura Becker uses an electric cart that Dan made using parts from an old motorized wheelchair. Her lap tray, also designed by her husband, is secure without being attached to a wheelchair. She exercises with a bicycle-like machine designed to give her upper and lower extremities a workout at the same time.

The Beckers' personal interest in assistive technology has led them to develop a small business, Becker Industries, Inc., to produce assistive devices for people who can't walk. Their patented "Scooter" board helps people with limited mobility move more easily into and out of a wheelchair, and reduces problems with skin breakdown for persons with spinal cord injuries. The Scooter board and other Becker Industry technology has been made available to individuals, hospitals, and rehabilitation facilities.



"I want to use my talents to help people get equipment that is both affordable and practical," says Becker. "Eventually, I want to employ people with disabilities in the manufacturing of these products."



Out in the Becker workshop a number of experimental projects are currently underway—a "reacher" that a person in a wheelchair can use to extend their grasp; counter-balanced or motorized shelves that move easily to eye-level; a weight machine with easily adjusted tensions for exercising. The Beckers believe these products have the potential to help people with a variety of disabilities. But they are very frustrated with the lack of funding available for research into assistive technology.

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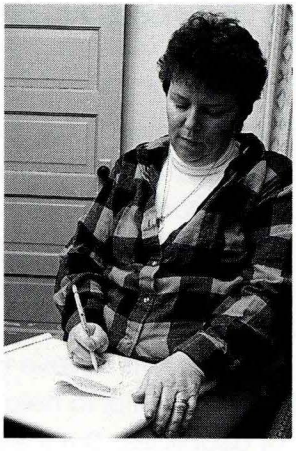
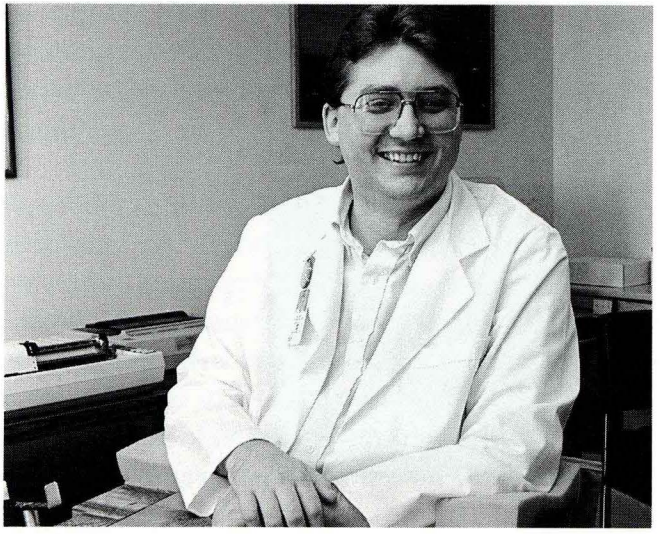
"We feel like we're continually swimming against the tide... We have ideas that can help people, but it takes money to develop these products."

"Cost and availability are two of the many barriers we face as people with disabilities when we look at products made by companies with no personal understanding of what it is like to have a disability," says Laura Becker.

"We feel like we're continuously swimming against the tide," explains Dan. "We have ideas that can help people, but it takes money to develop these products. We aren't asking for a handout, but we will have to stop developing new technologies unless money becomes available for this kind of assistive technology research and development." ■



Daniel Clark



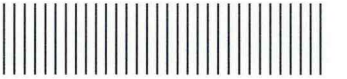
One of the most significant effects of becoming disabled is the way that this can isolate a person. Facets of life taken for granted—transportation, employment, even just having an accessible place where you can get together with friends—all become more difficult.

Perhaps this is one of the reasons **Daniel Clark's** involvement in the lives of others is his key to really living. Clark is an occupational therapy associate at the Iowa Methodist Medical Center in Des Moines. As part of his job, he assists with outpatient assessments, teaches computer skills, and designs computer activities for Rehabilitation Center patients with traumatic brain or spinal cord injuries.

One of the most significant effects of becoming disabled is the way that this can isolate a person.

Clark himself was injured in a diving accident in Arkansas when he was nineteen. Following the accident, he was hospitalized in an intensive care unit for five weeks, and then flown back to Iowa where he began the hard work of rehabilitation at Iowa Methodist. The next four months of his life were filled with physical and occupational therapy, much of which focused on learning new ways of doing things.

This period of training was very important. Clark adapted to new ways of writing, eating, and lying down. He learned to use a range of assistive technologies, both "high" and "low" tech, from an adapted spoon to the electric wheelchair and computer that are now an important part of his work and mobility. He uses a hand brace when



he writes or types, and a very simple tool—a pencil which he positions in his hand brace—allows him to type faster and with more accuracy.

He credits his rehabilitation at Iowa Methodist with teaching him how to use this technology to live as independently as possible, and says, "Without these assistive devices, my expectations of life would have been so much lower. With them, I can do so much more. But you have to be creative, not only in how you use them, but also in discovering how and where you can get them."

When he left the confines of Iowa Methodist to return home, Clark discovered that he had a problem with a very basic accessibility issue—getting in and out of the house in his wheelchair. His parents replaced a window with a door and ramp. The high cost of medical expenses and attendant care have meant that Clark—now 23—continues to live at home.

Clark, a graduate of Des Moines Area Community College, had a hard time finding a job at first. Today, his work in rehabilitation therapy is professionally rewarding, and the group health insurance that came with this position helps him meet the costs of the assistive technology that he uses to be more independent.

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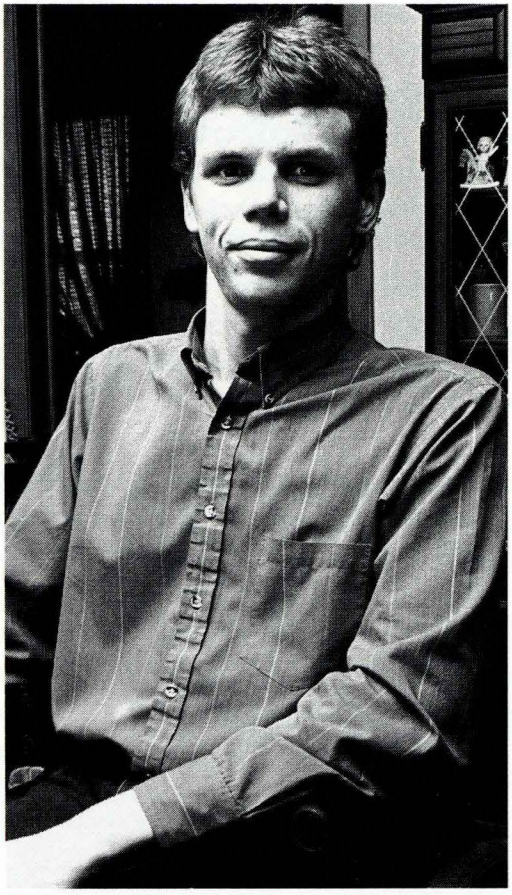
In order to work, you must be able to get to your job—a concern that limits the employment options of far too many rural Iowans with disabilities...

In order to work, you have to be able to get to your job—a concern that limits the employment options of far too many rural Iowans with disabilities. Clark says he is lucky to be able to travel to work on Des Moines' accessible Paratransit system. He also owns a van that has been adapted which allows him to move around in his community—in his words, to "do more socializing."

Dan Clark is openly enthusiastic about the difference assistive technology has made in his life—the devices he uses on his job, the modifications to his home, the ability to get to and from work, the chance to be out and about in the community. "Assistive technology has opened up areas to me that I could never have imagined," he explains. ■

David Gosch



David Gosch of Schleswig, Iowa, wants to farm when he graduates from high school this spring. To do this he will use, in addition to the traditional tools of the farmer, a variety of special tools—assistive technology—to bring in the crops and care for the stock.

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...in addition to the traditional tools of the farmer, he will use a variety of special tools—assistive technology—to bring in the crops and care for the stock.

"Ever since I was a little kid I've wanted to be a farmer," Gosch explains. "I like the variety of farming. Everyday you get to do something different; it's not like working in a factory or an office. I like being outside, driving the tractor, helping with the animals and working on the land."

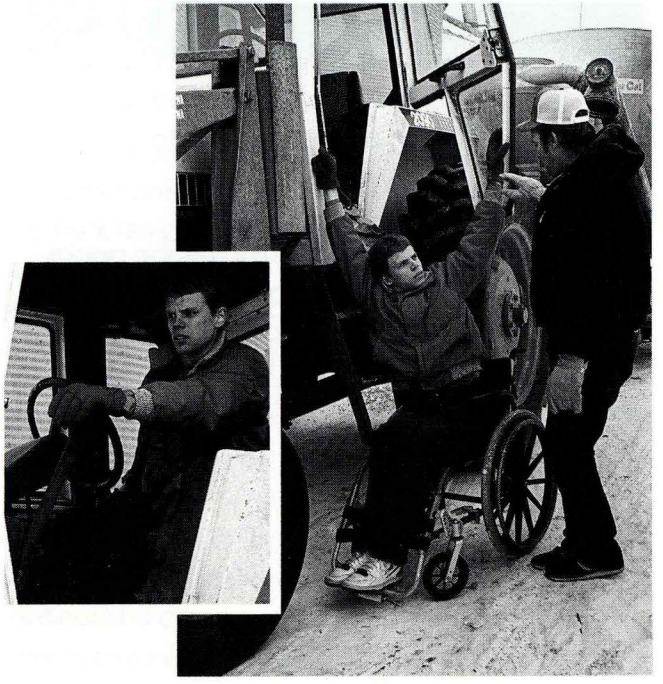
When David Gosch was two and a half years old, his parents learned he had lost 90% of his hearing. Then, in June of 1986, an accident resulted in the paralysis of his lower body.

Nonetheless, David Gosch takes an active role on the family farm, where he lives with his parents Marc and Sharon, his brothers Matthew, Christopher and Nathan, and his sister Jamie. Gosch is also active in his school, church and community. He has been treasurer of his church youth group and is a former member of 4-H. At school he uses an elevator to get to his classes, classmates take notes for him, and he has used a Phonic Ear (Telex Wireless FM System) to better understand spoken language.

David Gosch is an important member of the team that makes the Gosch family farm a going business. "Last fall he hauled 20,000 bushels of corn for me," says Marc Gosch. David also feeds the cattle and helps vaccinate baby pigs. His father believes that with the proper adaptive equipment, he could easily handle other hog management practices such as tail docking.

David Gosch uses a variety of special tools—assistive technology—in his work, among them hand controls to drive the lawn mower, the two tractors, and the car, and a chair-lift to get on and off machinery.

Finding the right technology is often a problem. "It's hard to find the assistive devices that you want," explains his mother. "Sometimes even the agencies that are supposed to help you don't know where to find what you need."



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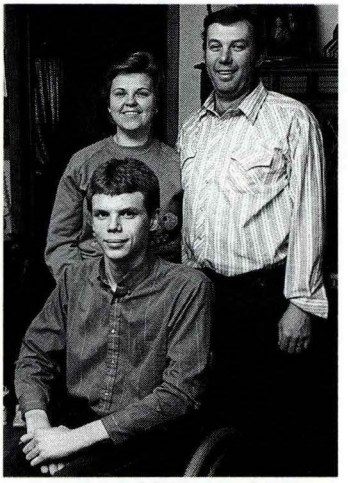
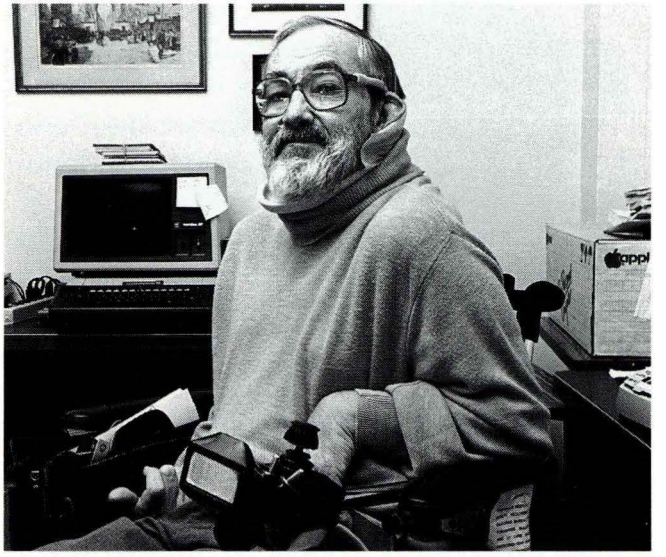


In their search for the right tools for the job, the Gosch family has tapped the skills of Easter Seals' Farm Family Rehabilitation Management (FaRM) program to locate or create the technology that David uses on the farm. It has been a good partnership; FaRM Director Therese Willkomm praises the teamwork of family and community, and says, "David, his father, and the community in Schleswig have been able to work together to modify a lot of the equipment he uses."

David Gosch's next goal is to get a lift that attaches to the tractor itself. "Right now," he explains, "the chair-lift is in the machine shed. Without a lift right on the tractor, I have to go back to the machine shed any time I want to get on or off the tractor, or else Dad has to help me transfer."

Marc Gosch is currently teaching his son about bookkeeping, and is encouraging him to take courses in accounting and computers as well. With these new "tools," David Gosch's farm responsibilities may be even broader, come graduation. ■

Tom Linde



How important is assistive technology for someone with complex disabilities? Ask Tom Linde, and he'll tell you. "Without technology I suspect I'd be little more than a vegetable," says Linde. "But by using technology—my chair, the computer, my speaker phone—I can maintain myself and do my work. They give me greater opportunity to act effectively with and for my patients and to communicate to others on the staff."

Tom Linde was born with cerebral palsy. After completing his doctorate in psychology, he continued a career as a clinical psychologist at a neuropsychiatric hospital in Knoxville, Iowa, where he has worked since 1971.

"Assistive technology gives me greater opportunity to act effectively with and for my patients and to communicate to others on the staff."

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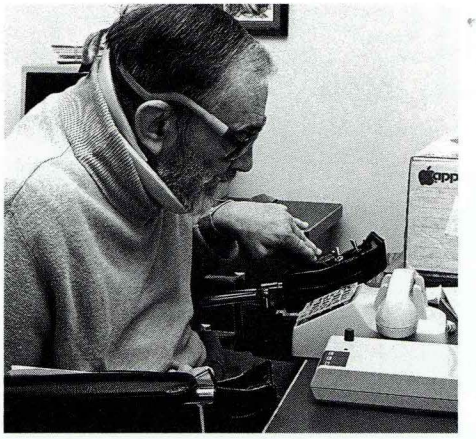
"The greatest barriers I've faced are the lack of knowledge of rehabilitation personnel...and their skepticism about my potential..."

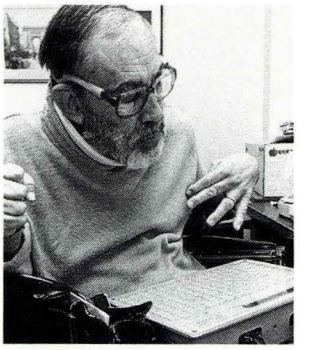


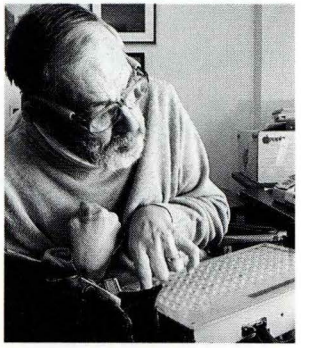
Linde credits his parents with constantly challenging him, giving him a broader sense of who he was and what he could do. One of the ways they did this was by finding—or developing themselves—assistive technology he could use. "I learned to look at myself in a positive light, " he explains; "to use the abilities I have, and not to focus on what I cannot do."

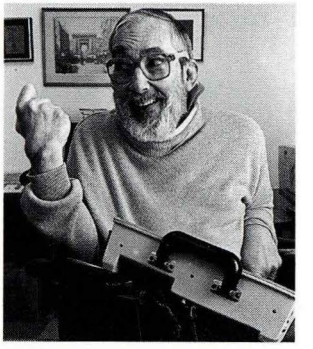
"The greatest barriers I've faced," says Linde, "are the lack of knowledge of rehabilitation personnel about assistive technology and their skepticism about my potential to become more productive through its application. Sometimes the negative attitudes of such workers have really affected my positive self-image."

The education of rehabilitation professionals about assistive technology and its capacity for expanding human potential is crucial. The field is one in which new advances are made daily; rehabilitation counselors must know not only what technology is both appropriate and available, but where to get it, how to maintain it, how to train an individual to use it and, in many cases, what sources of funding are available to assist a person to purchase it.

Medical center staff who work with Linde view him not as a person with cerebral palsy, but as a fully qualified fellow professional who happens to use assistive technology. Linde makes use of a full range of high tech and low tech devices—an ordinary soda straw to facilitate drinking, a modified computer for managing his client load, a speaker phone to communicate more clearly and easily. If a listener has trouble understanding his speech, he may talk using a device that provides an artificial voice.







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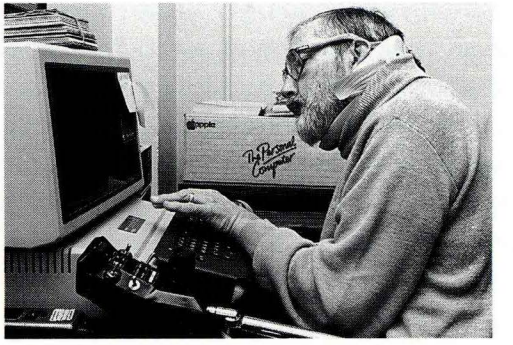
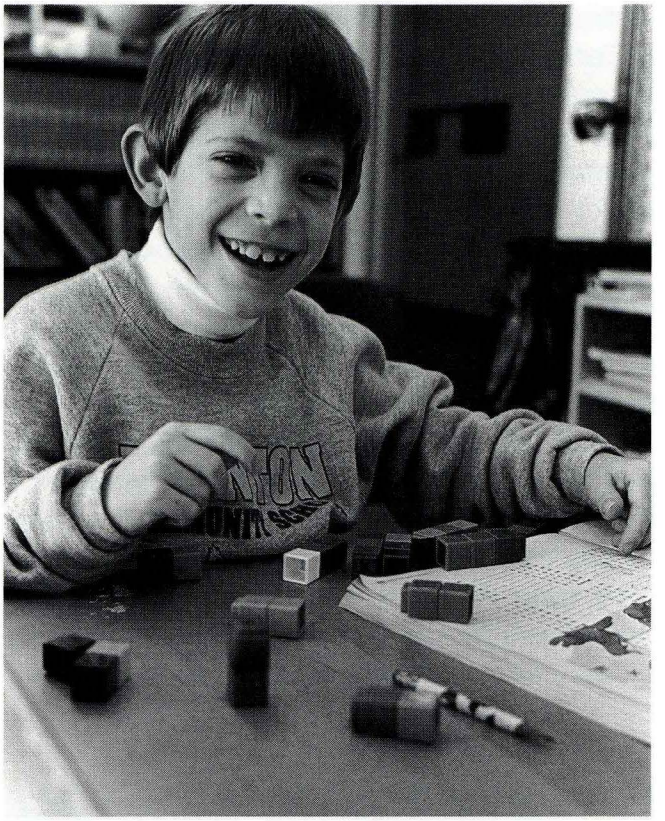
"...you have to view yourself not in terms of what you lack, but in terms of what you have."

When the partnership between the individual, the rehabilitation profession, and assistive technology works, the outcome is the kind of independence and personal satisfaction experienced by Dr. Linde. Linde feels that his success can serve as a bridge to understanding for the clients he serves, a lesson that you have to view yourself not in terms of what you lack, but in terms of what you have. "I see myself as a model for what can happen," says Linde, "and I hope that this motivates others to understand their own potential." ■



Justin Novak



Justin Novak is a busy third grader at Benton Community School in Atkins, just west of Cedar Rapids. Born with a heart defect, Justin then developed seizures. His parents later learned that, due to brain damage, he could not speak.

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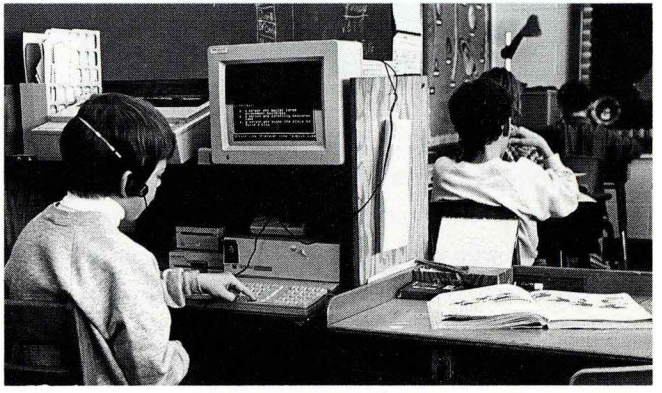
... at Taylor School, Justin's family began to learn about ways he could use assistive technology in the classroom and at home.

Justin started school at Taylor Elementary School in Cedar Rapids. It was while he was at Taylor School that his family began to learn about ways he could use assistive technology in the classroom and at home. His mother, Marsha Novak, explains, "They had various consultants who came in to demonstrate different devices that could benefit him."

At Taylor School, Justin was able to tap a variety of services, including occupational therapy, physical therapy, and speech therapy. He was mainstreamed into the regular classroom when he was five. Since he did not talk, finding a way for him to communicate with his classmates was a first priority. At school, he has learned to use an Apple computer programmed to help with both schoolwork and with speech. The computer has



made a big difference in his life. "Justin is reasonably intelligent, " Marsha Novak explains, "and his future looks so much brighter because of the computer."

At home, his family developed a variety of methods to communicate with Justin, including variations of signing. The Novaks also purchased a computer system for Justin to use at home that is identical to his system at school.

Two years ago, Justin started first grade at Benton Community School in Atkins. There, he has a personal assistant who helps with the computer and other classroom concerns. Doris Marcowitz, his third grade teacher, believes that without the computer Justin would find being mainstreamed much more difficult. The computer lets him talk with his friends, and also makes schoolwork easier.

Today, Justin is nine years old. He is just beginning to write, and his concept of words is steadily improving. "Two kinds of students make up Justin's friends," says Marcowitz, "those who like to do everything for him, and those who let him do whatever he can, and stand behind him as a back-up."

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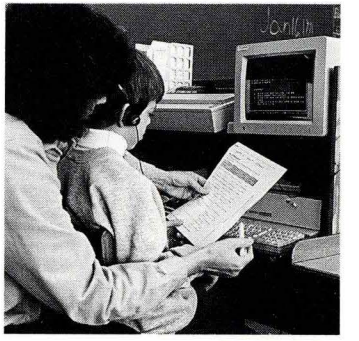
"The computer has made a big difference in his life... his future looks so much brighter because of it"



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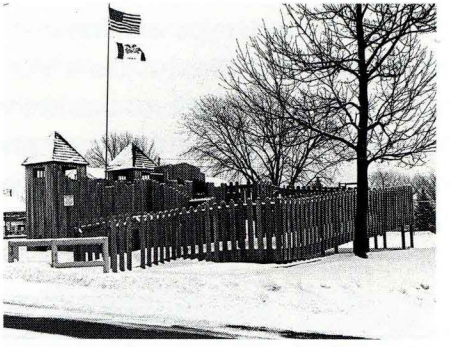
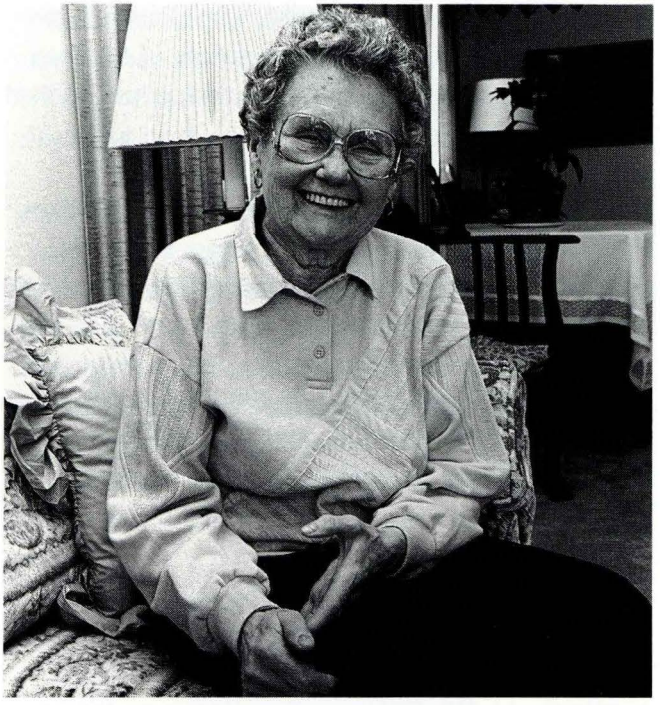
"Some people... are more protective of Justin than we are, but we know that he needs to grow up in the real world."

His mother feels that living in a small town is a real plus for Justin—and he has become a welcome member of the Atkins community, so much so that the city park's wooden fort now has a ramp to make it easier for Justin to play with his friends. "Some people in our community are probably more protective of Justin than we are," his mother says, "but we know that he needs to grow up in the real world." ■



Johanna Van Houten



On paper, Mason City's **Johanna Van Houten** is 78 years old-- but you'd hardly know that from talking with her. Legally blind since 1986, Van Houten leads a busy and independent life. "I have what's called *macular degeneration*," she explains, "but basically that's just wear and tear on the eyes. Usually older people who lose their sight have a spouse to help them, but I've been a widow for 13 years, so I've had to learn to manage on my own."

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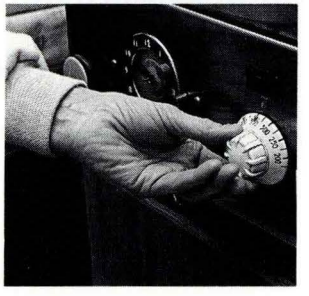
She relies on a variety of assistive devices, most of them everyday adaptations that require very little technology.



In spite of her limited eyesight, Van Houten is an active retiree. She relies on a variety of assistive devices, most of them everyday adaptations that require very little technology.

Van Houten is a volunteer at St. Joseph of Mercy Hospital, likes to play cards—bridge, 500, and pinochle—at the senior citizens' center, and enjoys literature.

To play cards, she uses cards that are slightly larger than usual. "I find I have difficulty distinguishing between hearts and diamonds, she explains. " But I play with nice people. If I make a mistake, they overlook it."

At home, her thermostat and the dial on her oven are clearly marked, but cooking has become increasingly difficult because she can no longer read the recipes. "I eat lunch at the senior citizens' center," she explains, "and when I'm home alone, I often just eat cottage cheese and some fruit."

Van Houten says, "I do wish I could read the daily paper, to get the gossip if nothing else." She has access to recorded books and magazines through the Iowa Department for the Blind. "Sometimes I think I would like one of those Kurzweil Readers that turn printed materials into speech," she muses, "but they are so very expensive.

"I have learned at least the basics of braille," Van Houten continues. "My daughter wanted me to, in case I needed to read instructions on a medicine bottle or something like that."

Van Houten uses public transportation to get to the senior citizens' center and to the hospital. "I ride the bus all the time," she says. "It only costs 50 cents. The only problem is that it doesn't run on Saturday or Sunday, but I have a friend who will pick me up to play cards or go to the hospital for lunch."

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"I ride the bus all the time... the only problem is that it doesn't run on Saturday or Sunday..."

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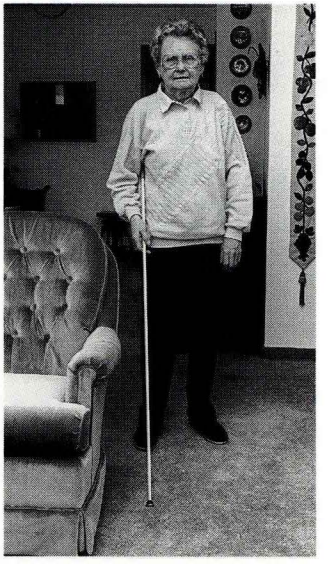
"The first time I used the cane, I cried all the way to the hospital. I hated it. Now I would have to say it's my best friend."

When the bus isn't convenient or available, Van Houten walks. She uses a white cane to get around, and comments, "The first time I used it, I cried all the way to the hospital! I hated the cane! I guess I was just like all those other older people who don't want to use a cane. Now I would have to say it's my best friend."

Van Houten treasures her independence, and says, "I have some problems, of course, but people tell me that I get along very well." ■



Summary

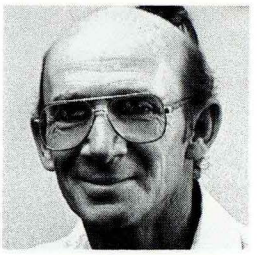
The Iowans you've just read about have all managed, to a significant extent, to find or create the assistive technology they use to be more active, productive members of their communities.

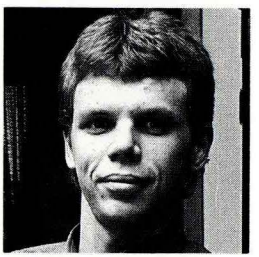
None of them would tell you that accomplishing this has been easy. The barriers they mention are similar to those named by other Iowans as they talk about trying to get appropriate assistive technology:

1. A limited public awareness about new assistive devices and services. Assistive technology can't be used by someone who doesn't know it exists. Individuals with disabilities and the persons who provide services have to be kept informed about assistive technology and services. Service coordination and communication among providers is essential.

2. A limited number of persons knowledgeable about and trained in the use of new technologies. Simply knowing new technologies exist is not enough. Service providers must also be trained in the use and maintenance of assistive technology.

3. A limited amount of funding for research and development. Often advances in assistive technology are made by persons with disabilities themselves, or by companies who specialize in this technology. But it takes funding to move from a brilliant idea to an actual device, marketed at a reasonable price.





4. Finally, perhaps one of the more serious barriers is the high cost of assistive technology. An electric wheelchair will cost from $3,000 to $8,000. A computer-assisted communication device can easily run $2,000. The majority of persons with disabilities have limited incomes, and high costs often mean putting off a purchase, or foregoing appropriate technology altogether.

Why is it important that Iowans have access to appropriate assistive technology? Ask yourself these questions: What is the cost to the community when it loses a potentially productive member because that person couldn't afford the technology he or she needed? What does it mean when Iowa loses the potential of a Tom Linde or a David Gosch?

Assistive technology devices and services have a real effect upon quality of life. They expand human potential.

Quality of life... human potential. These are fairly abstract phrases until you consider what they mean in terms of real Iowans, who lead real lives, and who make very real and very important contributions to their families, their communities, and the state in which they live.

For More Information

For more information, please contact:

Iowa Program for Assistive Technology
Iowa University Affiliated Program
University Hospital School
Iowa City, Iowa 52242
319-356-4391 *(voice /TTY)*
319-356-4382
1-800-348-7193

For information about the availability of commercially available assistive devices, used assistive devices that are available for sale, and assistive technology services, please call:

Assistive Technology Information Network
1-800-331-3027 *(voice/TTY)* for Iowa and Minnesota
319-356-3252 for other states

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