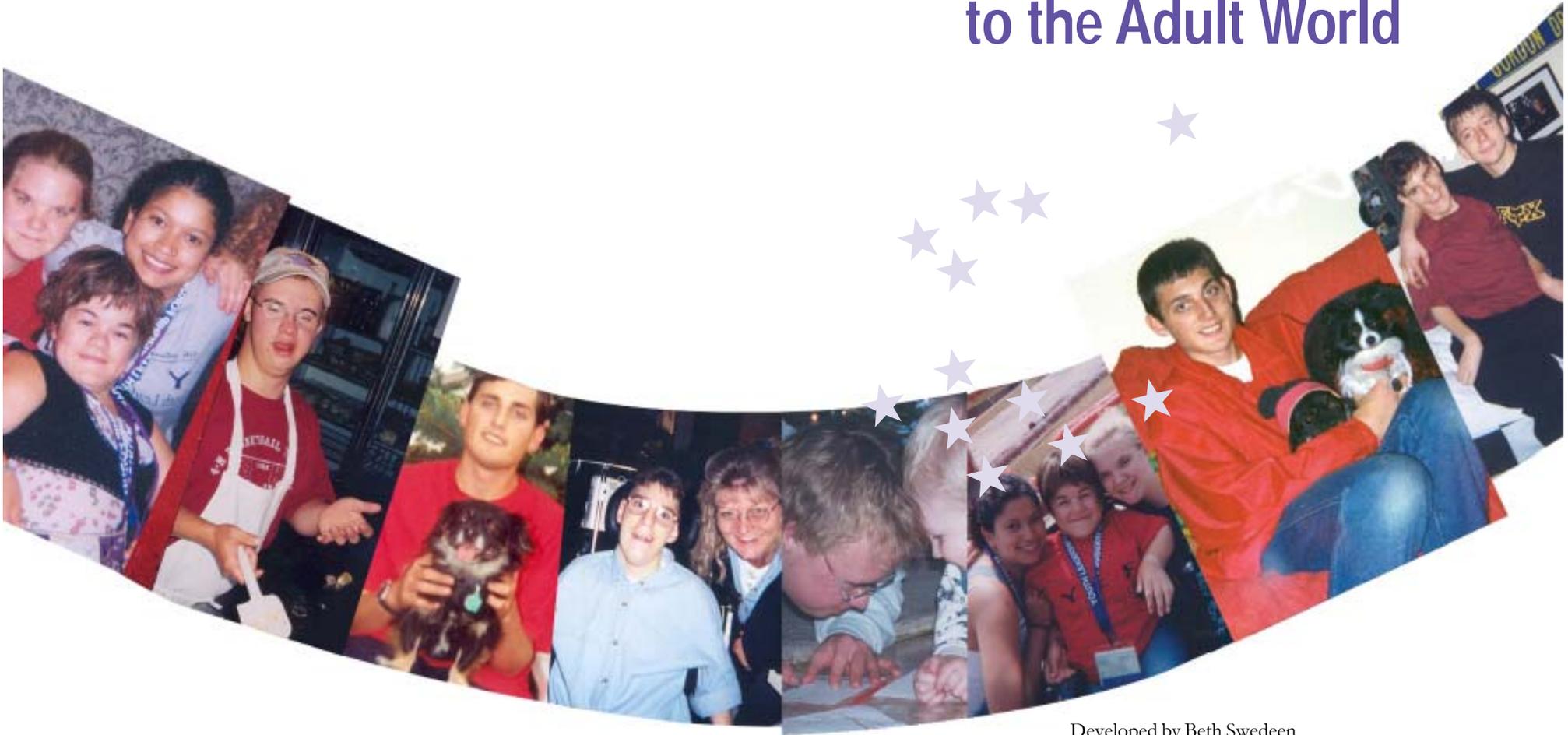


Wisconsin Healthy & Ready to Work
A Series of Materials Supporting Youth
with Special Health Care Needs

Stories of Transitions to the Adult World



Developed by Beth Swdeen

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Preface

The road to adulthood is rarely smooth, even for young people who have had the best possible preparation. When a young person has a significant disability, that journey can be even more challenging. Work experiences can be harder to come by and require more support. A young person may have to learn how to manage medications and talk to doctors along with learning how to cook and balance a checkbook. Inadequate transportation and long county waiting lists further complicate the ability to live and work in the community.

In the following pages, you will meet four young people with very different strengths, gifts, interests and concerns. However, they all share the desire to live full, productive adult lives where they can contribute to their communities. All of them also can point to some key people who have been instrumental in helping shape their dreams into reality.

Their stories are not meant to be a set of driving directions toward the ideal transition. But hopefully, these young people's stories can get readers thinking about a variety of possibilities they may not have explored before.

Andrew - August 2003



“My goal is child care because I like children – that’s the point. I like working with 3- and 4-year-olds best.” - Andrew

Andrew has had a clear vision about his future career for a long time. Inspired by his 19 nieces and nephews, he knows he wants to work in a daycare as a child care assistant.

Andrew, who is 20 and lives in southeastern Wisconsin, has plenty of experience.

He routinely takes care of seven nieces and nephews at one time. He has volunteered in his county's Birth-to-3 program, and volunteers in a local daycare center during the school year as part of his school program. He also is a junior leader with his 4-H Club, and helps the beginning members with their foods projects.

Andrew, who has Down syndrome, started volunteering during his middle school years, when he helped first graders with their

reading. He went on to help teach swimming at the local pool and to be a volunteer with the local recreation department's program for younger children. He also has helped coach basketball.

And one of his volunteer jobs has led to a paid job. Andrew started volunteering as an interpreter several years ago at Old World Wisconsin, where he shares

information about the old breed farm animals and antique toys with visitors. But his outgoing personality and strong work ethic eventually landed him a job in the museum's restaurant, where he busses and cleans up.



One of his bosses, Gary, says Andrew is a great employee in a position where it is hard to retain good workers. He chats with customers, can meet work deadlines, and is dependable.



found that a few simple accommodations worked well. She types out directions for Andrew because he works best with clear expectations and he can't

always read her handwriting.

His father, Enno, says their family began talking careers early with Andrew. In the past, he's wanted to be a football player, a doctor, and a fireman. But Andrew settled on child care after considering many variables.

"Aside from the fact he does an excellent job, there's a need all over

the country," Enno says. "Child care positions are available in every

community, and Andrew could still find a job while living close by whenever he is ready to move out."

Enno and his wife, Bea, have focused on community opportunities and experiences for Andrew since he was little. The youngest of six children, Andrew got some of his earliest job experiences – including milking cows – through visiting his grown siblings at their own homes.

Andrew's job at Old World Wisconsin has led to other dreams for his future, including

"He's a great employee and a real asset in the workplace." – Gary (Andrew's boss at Old World Wisconsin)

working as a waiter in a nice restaurant. He also plans to have a girlfriend, own his own house, and eventually get married. "In ten years, I'll be married and driving a Mercedes-Benz convertible," he says.

Like his job at Old World Wisconsin, Andrew's child care ambitions started as a volunteer experience with nieces and nephews: his sister-in-law needed an occasional babysitter. And as with his cleaning job, Andrew's sister-in-law

"From the time Andrew was very, very young, we've insisted on full inclusion," says Bea. "He attended a Lutheran day school through sixth grade, and then we decided to home school so Andrew could spend more time out in the community. With a flexible schedule, he could do academics in the morning and community activities in the afternoon. That's why he's had so much time to volunteer and gain all these wonderful experiences. And people in the community know Andrew."



trips with his parents to Europe. Bea and Enno say it can be scary to let Andrew try new things, but the risks have always paid off.

Last year, Andrew enrolled in his local high school to take some of the necessary child care courses he will need for child care assistant certification. While their local technical college refused to allow him to take the courses through their program, Andrew's parents say the local high school was very welcoming. He was on the Honor Roll after his first semester. This year, he is taking world history, English, computers, and child development with the help of a note taker. He should have his certification at the end of this school year.

One of their family stories revolves around the first time Andrew went to overnight church camp, along with classmates from parochial school. Some of the other kids at camp made mean comments about Andrew, but his classmates spoke up and put a stop to it.

"I love to watch those kids, even today," Enno says. "Just because they knew Andrew,

"Classes in child care are hard, but I'll succeed." – Andrew

they learned to be comfortable around people with disabilities. He taught them an important lesson."

Today, Andrew has had many experiences away from home: church youth trips to other states, 4-H Congress for a week in Madison, and

One of the biggest concerns for Andrew's

parents was the high school bus, but Bea said it turned out fine. On the very first morning, another student sat with Andrew, introduced herself, and started chatting. They have remained friends since.

In fact, Andrew's school relationships proved to be critical to his well-being a few months later. Last spring, Andrew was staying home alone and caring for an elderly aunt while his parents spent a long weekend out of town. On the school bus, he found he couldn't breathe and was having severe chest pains. Some of his friends on the bus alerted the driver, who called an ambulance.



With the support of his family and friends, Andrew continues to set new goals all the time. Right now, he is focusing on getting a driver's license. Like everything he has accomplished, his family helps him move forward a step at a time. He started by learning to use a riding lawn mower. Then, his father let him practice driving in their long, winding driveway. He is getting the driving manual to study for the written test.

It turned out Andrew was suffering from pericarditis, a painful viral infection that mimics a heart attack. Without the assistance of his school friends who knew him well, he might not have gotten the medical attention he needed.

"My goal is to take care of myself," Andrew says. "My job at Old World is important to helping me reach my goals. My friends have been important, and so has hard work. Classes in child care are hard, but "I'll succeed."

"I just keep thinking what if they hadn't taken him seriously and had just dropped him off at home?" Bea says. "Thank goodness he had friends looking out for him."

Stephanie - August 2003



"I've grown up with medical issues, and my mom says I'm good at talking to people, so a career as a doctor makes sense." - Stephanie

At age 16, Stephanie already has a huge rubber tub full of awards and news clippings at her home. She also has an equally impressive resume of activities that include typical high school endeavors: National Honor Society, forensics, mock trials, student athletic trainer, part-time jobs.

As a high school junior, Stephanie knows she wants to attend St. Norbert College, a small, private school not far from her northeastern Wisconsin home. She will pursue pre-med with a major in either psychology or biology, and plans to apply to medical school in either Madison or Milwaukee with the ambition of becoming either a cardiologist, oncologist, or sychologist.

But Stephanie's resume also includes some exceptional experiences: published poet, keynote speaker at statewide Developmental Disabilities conferences, and Rotary Club Ellsworth Peterson Award.

"I love to watch Discovery Health on TV," she says. "We have a family history that includes cancer and heart conditions. I've grown up with medical issues, and my mom says I'm good at talking to people, so a career as a doctor makes sense."

Stephanie is a gifted writer, public speaker, and self advocate. She also has experienced multiple surgeries and

"When you give people the information on the company that can do the modifications, they're more likely to do it." – Stephanie

hospitalizations because of polyostotic fibrous dysplasia, a metabolic disorder that requires medication to relieve joint discomfort. She has used a power wheelchair since she was three.

Stephanie already has three part-time jobs: she is an attendant at the water slide at her local YMCA; she works in her aunt's coffee house; and she sells her beaded jewelry with a friend every Saturday at the local farmers' market.

Stephanie lives with her parents and 10-year-old sister, Meredith, with whom she is very close. Stephanie and Meredith go downtown together to shop and hang out, like to swim, and play Nintendo and board games together. Sometimes, Meredith admits, she sleeps in Stephanie's bedroom so they can talk.



care as the biggest roadblocks to meeting her goals.

For instance, Stephanie faces costs of \$30,000 or more to make modifications to a vehicle in order for her to drive. The vehicle itself could cost another \$40,000 to \$45,000.

"I'm not crazy about driving right now because it's such a big commitment and because of the cost," Stephanie says. In the meantime, the compromise their family has developed is that one of Stephanie's friends is allowed to use the family van when they want to go out together.

One reason the two girls can go downtown together is that Stephanie advocated for more accessible parking and curb cuts in her small, tourism-driven community. As the only kid with a physical disability at her high school, she also has made suggestions for modifications in bathrooms and other parts of the school.

One reason the two girls can go downtown together is that Stephanie advocated for more accessible parking and curb cuts....

Another big issue is personal care, especially since

Stephanie wants to stay in the dorms if she goes to St. Norbert's. She and her mother, Kathy, differ on the level of support Stephanie needs. Her mother wants her to have an aide at high school to attend to Stephanie's personal care needs, while the school has pulled that resource for this year and has developed a plan where Stephanie could ask another assistant for help if she needs it. Stephanie thinks that will work fine; her mother remains unconvinced.

"When you give people the information on the company that can do the modifications, they're more likely to do it," is one strategy Stephanie says she has learned in becoming an effective advocate.

As Stephanie transitions out of high school and makes plans for her future, both she and her family see physical accessibility and personal

Likewise, in college, Kathy is concerned about how Stephanie will get across campus during rainy, icy weather that would make her power chair unsafe. She worries about what would happen if Stephanie was driving and the van broke down. She wonders if Stephanie's future personal care attendants in college will be capable, committed people.

Stephanie, on the other hand, hopes that she can end up asking friends in her dorm to help her with the occasional personal care needs she has.

"I have a different definition of independence than most people. I would hate to know something could happen to my daughter and it could have been prevented but wasn't because others wanted her to be independent," Kathy says.

"If I know she can do it alone but it saves time when someone else helps her, save the time. On the other hand, I'm realizing I need to transition myself during Stephanie's transition to help her deal with these issues of getting things done and getting answers to questions. That's part of the process for both of us."

Kathy says one recent example of encouraging Stephanie's independence is when a tack became lodged in her wheelchair. Stephanie was willing to let it stay, but her mother encouraged her to call the pharmacy that repairs her chair to arrange for the tire to be fixed.

"She wants me to be more independent and realizes she will not always be there to make all the phone calls," Stephanie says. But Kathy also wants Stephanie to have all the tools she will need to make good, independent choices.

One step that Stephanie took this summer toward increased independence and a smooth transition was to attend University of Wisconsin-Whitewater's Youth Leadership Forum (YLF). The one-week camp for high school juniors and seniors with disabilities provides information they need to know

I'm realizing I need to transition myself during Stephanie's transition to help her deal with their issues of getting things done and getting answers to questions – Stephanie's mom, Kathy

about leaving high school, as well as an independent experience in the dorms. Many of the youth used personal care attendants whom they did not know for the first time. Stephanie brought along a friend who helped her.

Kathy says Stephanie wasn't sure about a camp geared toward youth with disabilities. But Stephanie says she learned a lot about the role of the Division of Vocational Rehabilitation (DVR) and is now asking them to come to her Individual Education Plan meetings this year. She also made connections to older youth with disabilities who have begun college, which she said was helpful.

"I liked traveling to Whitewater to participate in the YLF," Stephanie says. "I was nervous about getting a taste of college life away from home, being that it was my first time far from home without an adult. But everything worked out great. My friend that came along acted as my 'assistant' to help me in the shower and in the cafeteria. I felt mostly independent and I had a great time. It was difficult to leave all the new friends I had made."

Stephanie still corresponds with her friends from across the state who attended YLF. They talk on the phone and e-mail each other. The experience was a confidence-booster, and reinforced Stephanie's belief that relying on friends for some personal care needs can work.

Stephanie says the most important reason she feels so confident about the future, and so willing to try new things, is because of the support her family has given her. She feels they will continue to play a big role in her continuing independence as she moves toward college and a career.

"My parents have always encouraged me to do the best. My dad always wants me to avoid settling for the least, to go for the best and put forth all my effort," Stephanie says. "My mother is

"If I didn't have my parents and sister, I wouldn't be what I am today." – Stephanie

my idol, the epitome of my life. My sister is my best

friend. She is my confidant and someone who I can be myself with. If I didn't have my parents and sister, I wouldn't be what I am today."

Michael – February 2004



"Our dream is that Michael will live, not independently, but INTERDEPENDENTLY... - Michael's family

So says the one-page handout created by 19-year-old Michael and his family. They have such a strong vision for Michael's future that they felt the need to spell it out.

"Michael should be able to live with support in his own home. He should be able to contribute by working and volunteering in his community, and he would like to participate in recreational activities with people his own age. We believe that if we all work together, our dream CAN come true!"

This dream, not unlike the dreams of many families for their teens, has not been the typical experience for young people with significant disabilities in Michael's small northern Wisconsin town. Typically, children with disabilities have been placed in segregated classrooms and have graduated to sheltered workshops and group homes.

"We worked so hard to have Michael included in first grade, and now we're starting all over from scratch with his transition," says Michael's mother, Rose. "But Michael is not going to a group home or a sheltered workshop. That's not what's best for him."

Michael recently graduated from high school and enjoys shopping and hanging out with friends, jumping on the trampoline, and horsing around with his dad, Dave, and younger brother, Travis. He likes to be on the go, has a good sense of humor and enjoys interacting with others. His family can't imagine him living and working in a situation where he wouldn't have a lot of control over how he spends his time and who he spends it with.

Michael has cerebral palsy, which affects his movement, speech and vision. He uses a wheelchair, communicates by answering yes or no to questions, and needs help with dressing, eating, using the bathroom and navigating around his home and community.

Throughout school, Michael was involved in Cub Scouts, church youth groups and social activities through a "Circle of Friends" program that began in middle school.



"Starting in ninth grade, we said we wanted Michael out in the community, doing volunteer or even paid work. But the school seemed very slow about developing job opportunities," Rose said. "We tried several things, but we always seemed to end up back at square one."

Even with these experiences, Michael and his family did not realize the many challenges that transitioning from school to adult life would pose.

During Michael's senior year, he did work at four different volunteer sites in the community: the public library, a kindergarten classroom, a hunting club

In Michael's county, if a young person lives in a group home and works at the sheltered workshop, then most supports are already in place: transportation, a place to live, a place to work, job supports and personal care.

"Michael needs a job that keeps his mind busy and that's hands-on. He likes to have something in his hands all the time, and he needs to switch from station to station." – Michael's long-time friend, Amy

and an assisted living home. Unfortunately, the job sites lacked specific job descriptions and

expectations. Michael's friend Amy, who has known him well since seventh grade, says the jobs weren't well-suited to Michael's talents and strengths.

Consistent with his school experience, however, Michael and his family want a more individualized and less segregated experience based on Michael's strengths and choices. To make that happen, Rose and Dave realized they would have to start virtually from scratch.

"In a library, you have to be quiet all the time, and it's not very interesting," she says. "Michael needs a job that keeps his mind busy and that's hands-on. He likes to have something in his hands all the time, and he needs to switch from station to station. He would really enjoy something that he can say he made. And throughout everything, I think Michael has to have friends around him. That's all he ever wanted."

As Michael entered high school, they began talking seriously with school staff about preparing him for transition.

Michael's school district is obligated to provide specialized programming until Michael is 21, based on federal law. So, Michael can receive vocational training, job placement and transportation services from the school district for two more years.



some scheduling flexibility for days when Michael needs to attend to his health concerns.

Complicating the search for job opportunities has been Michael's recent health problems, which have resulted in frequent pain and major surgery. Recently, he spent weeks in casts that totally immobilized him. Frequent pain has often interfered with his ability to concentrate.

To follow up on this idea, Rose found a woman in the community who had done job development before, and was willing to talk to local businesses about hiring Michael. She quickly lined up a job at a local grocery store, and the manager was enthused about Michael working there. A young woman who had done personal care for Michael in the past agreed to work as his job coach. Everything seemed set. However, the plan fell through when the owner, who lives in a different community, was concerned about liability issues.

Because finding the right job or jobs is so important to their family and so challenging in a rural area, Rose worked with the school district to contract with the regional Cerebral Palsy Center to conduct a vocational evaluation that could help lead to more meaningful job experiences.

The county has estimated it would cost nearly \$4,000 per month to support Michael to live in the community by himself, so Rose is hoping they can find Michael a roommate.

Michael's surgery and continuing health concerns have put job

Some ideas that emerged include working in a grocery store or delivery work at a local auto parts store so that Michael can keep on the go. Both job options would keep him engaged with people throughout the day. A delivery job also might allow

hunting on the back burner for now. Another difficult dream to achieve for Michael has been finding the resources so he can move into his own place. Michael and his family want him to stay in his hometown, because he has a large extended family close by and many people in town already know him.

While a county administrator has been supportive of Michael finding his own place, he has pointed out that it is difficult to free up money to pay for Michael's personal care in his own home when a fully-staffed group home in the county has open beds.



succeed. Unfortunately, when you are working with multiple people and agencies, each question often produces two more questions instead of an easy answer, and everything takes more time than you would like," Rose says.

The county has estimated it would cost nearly \$4,000 per month to support Michael to live in the community by himself, so Rose is hoping they can find Michael a roommate – possibly a high school friend who could also provide some personal care and hang out with Mike.

While the family continues discussions about attendant care, they also are house hunting for a home that would meet Michael's accessibility needs and would be located within walking distance of the downtown area. Rose has investigated programs that assist people with disabilities in purchasing their own homes, including the Movin' Out program headquartered in Madison. She also has talked to the Independent Living Center and Community Action Project Services, which might assist with accessibility and rehab needs.

"We have had help from a variety of people who want Michael to

Rose says one of the most helpful advocates they have had has been Pat Kelly, from the Wisconsin Coalition for Advocacy. Rose met Pat at a Family Support conference when Michael was a preschooler. Pat's presentation about Circle of Friends and inclusive schooling helped Rose realize what Michael's life could look like.

Pat believes that the family's persistence in trying to create a better service system for Michael has been at the heart of Michael's success so far.

"It really is people like Rose who enlighten people with their vision and energy," Pat says. "Their family has never wavered from their belief about what Michael's life can be like. And he's had one of the best school experiences a kid like Michael could have because of their vision. The reason they are so passionate is because they are so solid in their belief in their son. They know what his future can look like."

Andy - November 2003



"It's important to look ahead to what you want to do and know where you want to go.... Right now, I like where I am." - Andy

At age 23, Andy knows exactly what he likes and what his limits are. He loves animals, gardening, and working with older adults. He has a hard time with loud environments, what he calls "the younger generation," and working so many hours that he ends up being stressed and anxious.

Andy lives in his own apartment in a small town not far from Eau Claire and has autism.

He feels comfortable driving, as long as it's within a 10-mile radius of his home.

He works part-time on the wait staff in a nursing home, often spends time at the library reading and checking out books, and takes meticulous care of his two dogs, a Chihuahua named Zippy and a Pomeranian named Fluffy.

He recently joined a church, goes to the YMCA to play basketball, and has taken one of his dogs through training to be certified as a therapy dog in nursing homes. He volunteers regularly with his dog, and often runs errands for his friends at the nursing home. He also has competed at the state Special Olympics competitions in basketball and track and field.

In middle school, Andy had a rough time.

Andy is pretty satisfied with the choices he has made as he transitioned out of

high school and into a job and community life. But it took several years, lots of questions on Andy's part, and the support of his mother and several other people in the community to get him where he is today.

In middle school, Andy had a rough time. He had not been diagnosed with autism yet, and both the school and his community assumed Andy's struggles were related to emotional problems. Andy grew up on a farm with four brothers.

He was on the wrong medications, and had few breaks from the noise and distraction of his large family at home and the fast pace at school.



“It took a couple of years of listening to Andy one problem at a time and coaching him around finding the right answers. It was extremely important to acknowledge his abilities and listen to his ideas. In the end, care coordination among several of us meant a lot to this family.”

But when Andy was 15 ½, his mother purchased a house in town. Andy’s older married brother moved in downstairs, and Andy rented a smaller apartment on the second floor. It was quiet and private. Andy could decorate it the way he wanted. His brother was right downstairs if he needed help.

Andy also acknowledges that this small group of engaged, interested adults played a big role in his successful transition.

Around the same time, Andy received a more accurate diagnosis and a better educational program to fit his needs at school.

In some ways, Andy’s transition could have been considered complete...But in other ways, he was still struggling.

“Socially, it was hard for me to be in a large high school,” Andy says. “My teacher helped me with that. Then I had Wynne, Pat, and my mom. If I needed to talk to someone or if I had a financial question, I could go to them.”

Andy’s teacher coached him on practical skills, like money management and social issues.

Pat acted as a liaison with Andy’s psychiatrist, putting him on the road to more accurate treatment and medication. At high school, Andy took a foods class to learn how to cook and driver’s education so he could prepare for getting himself around town independently. The school provided space so Andy could recover when the noise and fast pace were too much to handle. Andy seemed to be finding his niche, and graduated with his classmates in 1998.

Andy also made some connections with two other adults who continue to provide support from time to time: his county case worker, Pat, and the director of Wisconsin’s Western Region Children with Special Health Care Need Program, Wynne.

“I realized that if I was going to help Andy, I would have to build a relationship with him,” Wynne says.

After graduation, Andy began working at a sheltered employment site in a neighboring town. The hours were long. He had to take a bus at six a.m. that dropped him off well before his shift began at eight. He continued to feel uncomfortable around the people he worked with.



Now, Andy works one to three days a week, and no more than four hours at a time. The pace is slower, and he has plenty of time to himself. He enjoys chatting with the nursing home residents. “They know how to have a conversation,” he says.

In some ways, Andy’s transition could have been considered complete. He was living independently, was caring for himself, and had a job. But in other ways, he was still struggling. Fortunately, the adults in his life who were his supports recognized he was unhappy, and urged him to consider all his options.

He no longer has that constant feeling of anxiety that he experienced in high school and on his first job.

He no longer has that constant feeling of anxiety that he experienced in high school and on his first job. out government forms), he can drop by for a quick visit with Wynne or Pat.

“Andy was being pushed to work 40 hours a week. But he does so much better when he is not working full time,” Wynne says. “For him, full-time work caused incredible anxiety and stress.”

Andy realizes that he had to learn a lot of new skills, had to be willing to ask questions, and had to take some risks in order to make his transition successful.

Andy began scanning the want ads in the newspaper. When an ad appeared for food service at the local nursing home, he took the initiative and applied. Wynne and Pat helped him work out a budget so that he could pay all his bills, work part-time, and still receive some support from Social Security.

“It’s important to look ahead to what you want to do and know where you want to go,” he says. “But you also have to put in a lot of effort. I think I may try a different job as I get older, but it’s too early to tell now. Right now, I like where I am.”

About the Author

Beth Swedeen works as a community outreach specialist with the Healthy and Ready to Work transition project at University of Wisconsin–Madison’s Waisman Center. She has had the privilege of working with youth who have disabilities, their families, and transition providers around the state in an effort to build community supports and improve transition services for youth with disabilities.

She has two daughters, ages 13 and 11. Her 11 year old, who has a disability, is already active in planning her own long-range transition from school to a job working with animals, and from her home to her own apartment.