Upfront

We all go through transitions, times of major shifts in our lives brought about by age or circumstance. This issue of *ACN* focuses on a particularly significant and challenging transition—the seismic shift from adolescence to adulthood known as the "coming of age."

For young people in many countries, coming of age means moving out of their parents' home into an apartment or dormitory (perhaps with roommates), going to college and/or work, figuring out how to manage each day (when to eat, sleep, recreate, work, exercise, *etc*.), taking responsibility for their own finances, perhaps moving away from the town where they grew up, meeting new friends, dating without parentally imposed curfews and so on. Many individuals expect to get married, have a career, buy a car, purchase a home, have children, go on vacation and, of course, deal with future transitions (divorce, relocation, changing jobs or careers, illness, retirement, death, *etc*.).

Coming of age is a developmental transition, *i.e.*, everyone who is of a certain legally-defined age goes through it. Of course, the nature of the transition varies enormously from person to person. As the saying goes, "Growing old is mandatory; growing up is optional."

People with disabilities, particularly those with severe communication impairments, face enormous barriers when making coming of age

transitions. For example, social services for adults with disabilities are grossly underfunded. Thus, supports available in childhood and adolescence often stop at a time when more, not less, support may be needed. Many AAC professionals do not serve adults, and the professionals and agencies that do are often neither skilled nor prepared to help individuals who rely on AAC. In addition, the general public may be unfamiliar with people who use AAC, making it even more difficult for these individuals to take on adult roles in their communities. Finally, young adults with severe disabilities need to learn how to manage the complex web of agencies and

Clinical News

The coming of age transition

Today's mighty oak is just yesterday's nut that held its ground.

Lots of young people around the world rely on AAC. Many in this new generation have grown up in inclusive settings using speech generating devices and other assistive technologies. More than ever before, they can read and write (at least to some extent). Some are going to college; many already have some work experience. They want to have adult relationships and be able to choose their own living

arrangements. These young adults expect to participate fully in their communities. Tragically, our adult service systems are failing them. Our educational systems haven't done so well preparing them either.

While we all seem to agree that what ultimately matters for children who rely on AAC is the long-term outcomes of the services we provide them, there is an astonishing lack of sober discussion and useful information about how to help these children develop the skills and abilities they will need to make successful coming of age transitions. At the moment, the way we pass the torch from child services to adult services almost guarantees

that someone will get burned.

We all know that young people need support to make this important life transition. Families of children without disabilities begin making plans in early childhood because they know it takes that long to teach the social, academic, personal and strategic skills a child will need to be successful as an adult. In addition, parents intuitively understand that building social networks and supports outside the family are key to one's quality of life and perhaps a critical factor in determining how their offspring will cope as adults with adversity, crises and future transitions.[1,2]

Why then do AAC professionals wait until high school to begin talking about the coming of age transition for youth who rely on AAC? Too often our AAC interventions with children tend to focus on short-term goals like device selection, device operation, symbol learning, expanding utterance length, syntax and communicating with paid workers (*e.g.*, teachers, instructional assistants and therapists). Why aren't we, for instance, more attentive to building and supporting successful interactions with a network of potential communication partners (family, friends, acquaintances and unfamiliar partners) in the community?

supports (*e.g.*, personal assistants, transportation, *etc*.) they need to get through each day safely and productively. That, in itself, can be a daunting task.

This issue of *Augmentative Communication News* targets all AAC stakeholders. So please, even if you don't happen to work or live with young people who rely on AAC, read on. AAC professionals, family members and policy makers can positively affect the transitions of people who rely on AAC, both directly and indirectly, by what we choose to do today.

In *Clinical News* some aspects of the coming of age transition are discussed. The *AAC-RERC* section summarizes research completed at Pennsylvania State University with a focus group of 23 employed individuals who rely on AAC. *For Consumers* summarizes interviews with John Draper (who relies on AAC and is just finishing college) and Nancy Draper (his mother), as they reflect on John's coming of age transition. *On the Web* lists valuable

web resources. In *University/ Research* two follow-up projects are described. The *Equipment* section recounts Johana Schwartz's transition out of her parent's home and the impact on her use of technology.

Thanks to many people who helped with this issue. They include Hank Bersani, Barbara Collier, John Draper, Nancy Draper, Melanie Fried-Oken, Mary Hunt Berg, Carole Krezman, Shelly Lund, David McNaughton, Johana Schwartz and Hazel Self. To say that my consciousness has been raised is an understatement at best.

And please remember that change is inevitable (except perhaps from vending machines).
Sarah W. Blackstone, Ph.D. CCC-SLP

Nature of the transition

The coming of age transition often means that abrupt and major changes occur at some legislated moment, *i.e.*, an 18th, 21st or 22nd birthday. Of course, these changes do not happen all at once, or in the same way, or at the same time for everyone. Many individuals with severe disabilities make changes gradually, especially when appropriate supports are not available in the community, or families prefer the status quo. Without exception, however, adult service systems do take over, public education supports come to an end and daily activity options change. When transitions are not planned for in advance and/ or are delayed for decades, outcomes are likely to be poor. It is a lot easier to learn new skills and make changes at age 20 than at 60.

Families of children with physical and cognitive challenges are rightfully very cautious about "letting go" because they understand better than anyone their child's needs and vulnerabilities. They also quickly become aware of the limitations of available options for young adults in their communities. As a result, the coming of age transition can be enormously stressful for the whole family. A successful transition will mean supporting the family in ways that are meaningful to *them*.

Plan for tomorrow today

If children become adults who (1) continue to be treated like children or adolescents (minus the supports), (2) are not engaged in daily activities that allow them to pursue their own interests and reach their potential or (3) are struggling to survive on the edge of poverty, then childhood AAC interventions have not been effective. AAC professionals and organizations must become stronger advocates for the futures of young people. Early

on, it is important to develop children's communication, academic and social skills, foster high expectations and support their dreams. In addition, there is a myriad of other areas to address, such as building social networks, providing same-aged peer mentoring, fostering self determination, exploring living options and addressing issues related to safety, sexuality and self-esteem.

Building social networks. A successful coming of age transition requires that individuals have lots of experience communicating, not only with family members, teachers and therapists (as is often stressed on IEPs and ITPs), but also with a wider circle of friends, acquaintances and unfamiliar partners. Individuals with disabilities face unique challenges and need robust social networks for support.[3] Many people who rely on AAC continue to be at high risk for exclusion from the social networks typical of their peers, and face social isolation as adults. Even those who use AAC technologies and have sufficient independent communication skills to participate in social, educational and employment situations may find themselves marginalized, and their social status tenuous.[4]

AAC assessments, interventions and outcome measures that focus solely on AAC technologies and strategies are unlikely to lead to the establishment of goals or intervention plans that reflect many of the interrelated variables needed to build social networks and strengthen and expand participation and involvement in life situations.[5] The *Social Networks Inventory*[6] provides AAC professionals with an assessment and intervention-planning tool that helps individuals, family members and AAC practitioners to frame intervention goals so as to

Table I. Mentoring project	
Managing aides/ personal care attendants	1. Develop a checklist that enables you to give quick feedback to an aide. 2. Arrange training for a personal care attendant.
Building friendships	Focus on others first, then they may focus on you. Ask people about themselves.
Coming to terms with your disability	"You have to see yourself the same as everyone else. That's how you go on with your life."

develop skills that build membership and participation in the community.

The AAC Mentor Project. Janice Light, David McNaughton, Carole Krezman and Michael Williams worked with mentors and their 32 young protégés (ages 13-31), all of whom relied on AAC.[7] The mentors first received training in communication and problem-solving skills. Then, the mentor-protégé dyads had email discussions on a wide range of topics. Initially, the protégés identified transition goals they hoped to address as part of the project. Topics included:

college, employment and volunteer experiences, independent living, personal care attendants, assistive technology and computer skills, social participation and friendships, communication with unfamiliar partners and advocacy for self and others.

Interactions between protégés and mentors involved social exchanges as well as the above topics. Through email, protégés identified challenges and then their mentors helped them develop solutions. Examples are given in Table I. After completion of the project, both protégés and mentors reported positive outcomes. All highly valued the experience.

The SPEAK UP Project (Safeguarding People who Use AAC from Sexual Abuse/Victimization). This project, directed by Barbara Collier, surveyed 26 adults who rely on AAC about adult-related issues. The goals of the project were to 1) explore the

experiences and needs of people who use AAC in relation to abuse; 2) provide resources, education, vocabulary and strategies to respond to and reduce the risk of abuse in their lives and 3) provide support to community agencies that should play a role in responding to and preventing the abuse of people who use AAC. Project findings showed overwhelmingly that people who use AAC experience a range of abuses, including sexual abuse. They often lack information about healthy and abusive relationships, supports that would enable them to cope with relationship difficulties, abuse and justice services and have no means of communicating about sexuality or abuse. SPEAK UP staff have developed a number of products to address these areas, which are available online, at no cost. [See *On the Web* in this issue and below.]

Personal care assistants. "No matter where someone lives, their quality of life depends to a great extent on the degree to which they can direct the services of persons who provide attendant care," said Collier.[8] Most adults she has worked with over the years reside in supported living situations where they are required to direct their attendant services. Few reported feeling prepared to manage personal care assistants (PCAs) and many reported having to deal with between five and fifteen different people each week. Individuals who use AAC report they have neither the vocabulary, nor the strategies they need to direct their own services. They also lacked problem-solving skills in dealing with difficult situations. Examples of areas they wanted help with included (1) how to give feedback that is positive and constructive, (2) how to be assertive

and negotiate their own care and (3) how to deal with conflicts and difficult situations.

Resources: Collier, Barbara (1998). *Communicating Matters: A **Training** Guide for Personal Attendants Working with Consumers Who Have Enhanced Communication Needs*. Baltimore: Paul H. Brookes Pub. Co.

Collier, B. (2000). *See What We Say*. Baltimore: Paul H. Brookes Pub. Co.

Collier, B, Antonius K, & Blackstien-Adler S. (2001) *Communicate: A Communication Module and Home Study Program*. Dynavox Systems. Pittsburgh, PA.

Sexuality. In the Speak Up Project survey, eighty-eight percent of the adult respondents said they needed information about sexuality and disability issues. This included a desire to know more about sexual assistants, assistive masturbation, communicating with doctors without parents, diverse lifestyles and abuse.

Resources. *Promoting healthy sexuality brochure.* www.aacsafeguarding.ca/ Speak_Up_Brochure.pdf.

Browne J. & Mirenda, P. (1997). *Responding to an AAC User's Disclosure.* Available at www.aacsafeguarding.ca/resources-sexabuserespond.htm

Safety. Individuals who rely on AAC face many safety issues and are at risk for abuse. Survey data show that 75% had already experienced some form of abuse or crime, which had most often occurred in their residences, behind closed doors. Muggings were also reported. To reduce risks of abuse and crime, Collier recommended teaching individuals what to do if someone threatens them, neglects them, borrows something and doesn't return it or steals from them. Also, what to do if stranded, if a wheelchair doesn't work or if left alone without your technology set up.

Resources: Information about safety issues and resources for individuals who rely on AAC. www.accpc.ca/reducingtherisk.htm.

Self-esteem. Within the Speak Up project most of the respondents had

self-esteem problems. They told of being degraded throughout their lives and described a slow erosion of their sense of dignity. Some reported major problems with depression, anger management and addiction.

Collier recommended building feelings of self worth and esteem by creating a culture of entitlement and providing emotional wellness programs.

Counselors familiar with disability issues and with some experience in communicating with people who use AAC should be available where individuals reside.

She also suggested young people work on techniques to build inner strength and reduce stress by using meditation techniques, engaging in hobbies and participating in peer groups.

Independent living. Many individuals who rely on AAC usually require a considerable amount of attendant services. Before making a decision about where someone will live, families may want to explore all the options. The Gage Transition to Independent Living program, located in Toronto, is an example of a program designed to give young people with physical disabilities opportunities to develop self-confidence and learn and practice their independence skills. The Gage respects the rights of people with disabilities to live in their communities with the same control, self-determination and integration as other citizens. Program staff includes health educators, life skills educators and personal care attendants (PCAs). PCAs are taught to support, not direct the care of individuals they are hired to help.

The Gage has ten apartments associated with the program in downtown Toronto where individuals with physical disabilities, who require attendant care and want to learn and practice independent living skills, can live for as long as it takes to achieve personal

goals (*e.g.*, accessing community resources, budgeting, meal planning.)

The Gage also runs a program in partnership with the Bloorview MacMillan Rehabilitation Center that enables young people with disabilities to live for three weeks on a university campus to practice independent living skills.

Hazel Self,[9] Consumer Services Coordinator at the Gage, said, "clients who rely on AAC have to be familiar with their equipment and willing to use it." At Gage they learn to give instructions to PCAs and to modify things they want to say for different partners. She also noted that young people need to learn to be comfortable communicating with strangers.

Self-determination. A major goal for young people is the development of skills than enable them to make choices, solve problems and direct their own lives without interference.[10] Project TechTrans, directed by Melanie Fried-Oken and Hank Bersani, found that most (93%) high school students who rely on AAC do not even partially direct their own individualized transition planning (ITP) meetings. More than half do not even actively participate. To address this problem and foster self-determination skills in students, they developed the TechTrans Model.[11] It provides goals and strategies to promote well-planned high school transitions, address assistive technology needs and develop maximal self-determination. One product is the book *Me and My AT,* written by students about their assistive technology.[12]

Another excellent resource to support the development of self-determination is *Whose Future is it Anyway: A student-directed transition planning process.*[13] It provides strategies for engaging all students in the ITP planning process.

AAC-RERC

SPREAD THE WORD

Getting more out of school transition programs by David McNaughton

Children go to school to learn things that will prepare them for their futures as the next generation who will contribute to and participate in society. Parents and teachers ask, "What do you want to be when you grow up?" and children dream and fantasize about their options—policeman, teacher, doctor, pilot, parent, academy award winner. High expectations yield high performance. Low expectations leave kids behind and unable to catch up.

In 1993, I embarked on a series of studies to learn more about the experiences of individuals who rely on AAC and are employed. I hoped that these individuals might share important insights regarding transition planning by reflecting about their high school experiences and transitions to adulthood. As part of this research, which was carried out at Pennsylvania State University, 23 individuals participated in a web-based AAC focus group discussion on employment.[14,15]

Identifying the challenge

A majority of those who participated in the focus group said they had experienced difficulty obtaining needed services in high school. They recalled high school as a time when they struggled to gain access to appropriate educational activities. Many described experiences similar to Sam's.

> I was kind of pushed off to the side or passed over like I wasn't there.

Participants noted that teachers and clinicians are often in a unique position to provide support. All said that the intervention of one or more teachers who believed in their potential had made a critical difference in their lives. However, they also said many teachers and clinicians had only limited training in working with individuals with severe disabilities and so had struggled to develop effective interventions. In addition, the expectations of the educational system were often limited, and many educators and therapists were unaware that individuals who use AAC grow up to work, live independently (or with support) in their communities, get married, maintain relationships, have families and participate fully in society. As Sam so poignantly observed:

> It pains me to say that back in my elementary days, the thought of a "severely" disabled child holding a job later in life was foreign to my teachers.

A lack of continuity in educational programming from year to year also posed a major problem, and time was wasted trying to "reinvent wheels." In many cases there was limited awareness of both an individual's past accomplishments and the instructional approaches that had already proven to be effective. Teresa noted:

> The school district totally ignored my past accomplishments in regular education. People assume if you have CP and can't talk that you must be retarded. Even in classes I had to prove myself before teachers acknowledged me.

Making recommendations

Rarely do we have an opportunity to get feedback from those who have been through the educational system and who can reflect on their experiences in ways that can inform current practice. Participants in the focus group identified challenges,

> *I have had a couple of great teachers who have gone out of their way to support my educational and career goals.*

shared personal strategies and made recommendations for teachers, family members and younger students who rely on AAC. Their recommendations are summarized in Table II on page 6 and discussed below.

For teachers

Participants had three major recommendations for teachers:

1. Be a teacher who makes a difference. There are teachers who work hard to support the participation of individuals who use AAC in a wide variety of classes and activities; and there are teachers who don't. Despite the many demands on today's teachers, all need to understand that the transition years are especially critical for individuals who rely on AAC. If no one takes an interest in these students, or has high expectations for them, very few are likely to reach their true potential. Every teacher and every therapist need to set goals that are achievable and that also raise expectations. The contribution of a good teacher is remembered for a lifetime! For example, many years after graduation, focus group participants described the actions of a few teachers who had made a powerful difference in their lives. Comments included:

> I have had a couple of great teachers who have gone out of their way to support my educational and career goals.

> Tom, my counselor at my school, helped me get my first job.

2. Help plan for the future and prepare for the next environment. Transition planning for individuals who use AAC requires working through a broad range of challenges,

e.g., transportation, employment supports and independent living. These challenges are compounded when an individual also has severe physical and/or cognitive disabilities. Only actual experience in the desired activities, such as internships, work-study, summer jobs, *etc*., can possibly provide a clear sense of each individual's instructional needs. Sampling the next environment enables teachers, individuals who use AAC and their families to figure out what supports are needed and what skills should be taught. As Theresa reported:

> Internships have helped me reevaluate my career goals and gain experience.

In a modified form this approach can also help identify instructional goals for younger children. It is important to teach young children skills they will need later in life, *e.g.*, learning to ask for assistance in taking off a coat, to select courses in high school, to say *please* and *thank-you* or to write out instructions for a personal care attendant.

3. Assist students to develop problem-solving strategies and to solve their own problems. Transition planning should be a life-long, ongoing process, not a short-term event that occurs the year before leaving high school.[16] People learn to apply problem solving skills throughout their lives. Thus, we must know how to teach general problem-solving skills. It is just as important as giving a child the communication, social, emotional and academic tools they need to meet the challenges that will come their way.

For individuals to develop problem-solving skills, they must believe that their actions can make a difference. Thus, from a very early age children should be taught they

Table II. Recommendations for teachers, individuals who rely on AAC and family members		
TEACHERS	INDIVIDUALS WHO RELY ON AAC	FAMILY MEMBER
1. Be a teacher who makes a difference.	1. Document the work you have done and how it was produced.	1. Push for a curriculum that meets the goals of your child.
2. Help plan for the future and prepare for the next environment.	2. Think about your educational and experiencial needs beyond high school.	2. Pursue additional education opportunities, *e.g*., extracurriular experiences.
3. Assist students to develop problem-solving strategies and solve their own problems.	3. Ask for support in solving your own problems	

can control their environments through their actions and words. They need opportunities to make choices, play games and decide what book to read next or with whom to play. Teaching students specific problem-solving strategies can also help them realize that alternative solutions exist. Individuals who are given opportunities to solve their own problems are more likely to become self-determined adults who are ready to tackle life's challenges.

For individuals who rely on AAC

Participants urged students who rely on AAC to think beyond school and stressed the importance of developing self-esteem and learning how to promote oneself. They made three specific recommendations:

1. Document what you have done and how it was produced. Several participants said that the process of "reinventing the wheel" every year became frustrating. It was tiresome to demonstrate, again and again, the technology and other supports needed to produce top quality work. They suggested: (1) keeping a portfolio of work with sections explaining how work is produced, whether help is needed with proof reading, *etc*. and (2) making a videotape to show what can be accomplished when appropriate supports are in place.

2. Think about your educational and experiencial needs beyond high

school. All focus group participants who were employed full time had at least some college education, and some had multiple degrees. While opportunities for employment do not necessarily require a college education, some individuals felt they needed to be over-qualified before an employer would hire them. They suggested choosing courses in high school that keep the doors open to post-secondary education, at least until after career choices are made.

3. Develop support networks. Many individuals who were employed got important job leads from friends, relatives and other individuals familiar with their skills. Focus group participants recommended developing a network of people who are aware of the interests and abilities of a student and act as advocates. As one person noted, while personal effort is important, often "pull" will get you farther than "push." They also suggested that individuals regularly share news about their accomplishments with people in their networks.

> You want them to be aware of what you have achieved, and you don't want them to feel that the only time you get in touch is to ask a favor!

For family members

Participants suggested that the adults in each student's life should think carefully about the strengths and potential of that child. The family should specifically:

1. Push for a curriculum that addresses the goals of the child. Many participants believed that special education teachers were too easy on individuals who rely on AAC. Mike wrote:

> When I was 15 and had just come to the United States. . .my first math teacher wanted me to do basic math. I knew how to do algebraic equations already. In my first IEP, my mother had to fight for me to take Algebra 2.

Her fight was an all-important one. Mike went on to get a Master's degree in Astrophysics and a California teaching certificate. If his parent had settled for basic math, none of his career goals could have been met.

Focus group participants also pointed out that more supports are available in high school than in adult life. Thus, parents need to be strong advocates so that their child gets access to all available programs. In the United States, for example, current special education law (IDEA) requires that all individuals with disabilities have an Individualized Transition Plan at age 14. Parents also may need to support their children in learning how to assume lead roles in their own transition planning.

2. Consider additional education opportunities. Depending on where one lives, the school district may or may not have specialized programs in place for individuals who use AAC. Focus group participants recommended that families encourage their children to participate in extracurricular activities that help them gain expertise in the use of their communication system components. Also, they suggested that families find and participate in intensive two- or three-week programs that help both family members and adolescents/young

adults to gain skills that will support them in making a successful transition.[17]

Expectations and planning

Expectations during the school years are key to success. Bob wrote:

> My message to schools is do not have low expectations for your students. Do not cop out by saying, "Oh, this student will never do that. So we don't have to teach him this."….Always expect the best from your students and you will never be disappointed.

Two students, with comparable reading and academic skills, experienced very different educational outcomes because of their experiences in high school. One (Peter) dropped out because the school had low expectations.

> In the 11th grade of high school, I dropped out. I knew I was stuck in special education. I knew I was only learning half of what everyone else was learning, and I couldn't deal with that. I felt sick, very sick about being stuck in special education classes. So I dropped out.

The other (Teresa) graduated and went to college because of the support she got in high school.

> Once the school saw I could keep up with the nondisabled students, they were very supportive. During my last three years, I took almost all regular education classes, graduated, and went on to university.

Summary

A successful transition requires the ongoing efforts of the individual, his or her family, friends, teachers and other concerned professionals. According to focus group participants, positive outcomes are possible when the individual demonstrates a willingness to work hard to reach a goal, and when his or her family and involved professionals have appropriate expectations and provide the

necessary supports. Jamie wrote:

> After I turned 18, some people thought all I would be able to do was sit home or go into a workshop.

Jamie, through extensive personal effort and the support of both his family and caring professionals, went on to work for a Fortune 500 corporation and to start his own publishing business.

Similarly, Mike said he was able to get two college degrees, his California teaching credential and a full-time job as a classroom teacher, in part because his family and teachers believed in his goals just as much as he did.

> All of my special education and regular education teachers pushed me hard. They all knew I wanted to go to college and get a job. They did everything they could and then some, because, I think, they believed in my potential. Every teacher should think that way.

AAC-RERC
SPREAD THE WORD

AAC-RERC Webcast Series

The AAC-RERC announces a series of webcasts on various AAC and communication-related topics. **Dr. Janice Light** will present on *AAC Interventions to Maximize Language Development for Young Children* will beginning May 1, 2005.

Still available is the webcast by **Dr. David McNaughton**, *Supporting Successful Transition for Individuals who use AAC.* Upcoming topics are: 1. *AAC and Aphasia: A Review of Visual Scenes Display Project.* **Dr. David Beukelman**. August 1, 2005. 2. *An Overview of the Health-based Funding Programs that Cover SGDs.* **Lewis Golinker**, Esq. November 1, 2005.

To view the webcasts, go to the www.aac-rerc.com and follow the links for Webcasts.

For Consumers

Do Not Work on Me!

with John Draper & Nancy Draper

What is it like for a family to navigate through the coming of age transition? John Draper, a 24-year-old journalism major, reflects on his ongoing journey. Nancy Draper, his mother, adds her perspectives on this important family transition. The Draper family lives in Ontario, Canada. John has cerebral palsy and significant physical and communication challenges. He currently lives at home. John and Nancy were interviewed by email and phone.

Transition planning for individuals with complex communication needs should involve the family and begin early. John said a good age to start serious transition programs is between ages 14 and 16. However, planning for transitions should begin much earlier. He emphasized that families need to learn what is available for adults with disabilities.

"Professionals who view transition goals as a breaking away from the family are misguided," said Nancy. "Transition planning needs to start when a child is very young and should involve the family every step of the way. The reality is that adult services often have limited resources so when anything goes wrong, the family is called upon to come to the rescue. Thus, it is essential that family members know what is going on. The more prepared we are, the more able we can be to pitch in."

John and Nancy agree that it is not just the child's transition. It is very much a family transition, and a complex one at that!

Individuals who rely on AAC need to learn new skills to make successful transitions. When John attended the school system in Ontario, transition planning was not a formal process or requirement and he did not explore transition options at his high school. However, with the support and encouragement of his family, he visited the Gage Transitional Living Centre in Toronto, which teaches people with disabilities how to live on their own. He also participated in a three-week Teen Independent Program at a university, co-sponsored by the Bloorview MacMillan Centre and the Gage Centre. He learned to book his own attendants for personal care ("Having had attendants at home most of my life was a big help.") He also learned how to use elevators independently and to go to church by himself. ("It was the first time I ever went anywhere without someone with me.")

Nancy believes it is misguided to think that transition planning means simply figuring out what equipment someone needs, where he or she will work, go to school, spend the day, deal with transportation or even sleep at night. "Even if all these issues could be solved (which is difficult at best)," she stated, "a transition is not just a phase that happens. It is a long process that requires finding creative ways of living."

Independence training is helpful. Nancy said that a "go forth and be independent" attitude is just unrealistic. John noted he would have liked to learn more about independent living and money management skills at an earlier age, and indicated that independence training was helpful because "it points out things you need to think about." For example, John says:

> If I lived on my own and I was in bed and there was an emergency, it is a challenge to think about how I could solve the problem. Also, being alone, I would face challenges like my glasses being dropped, or my comforter falling off at night and getting cold because I have no way of pulling it up over me again.

He also discovered it was hard to do some of the daily activities other people take for granted.

> Laundry is a good example. I don't know if I would be able to direct someone to do my laundry. I know the colours and whites and that's it. I am unsure what comes after that.

The transition period can mean coming to terms with society's views on disability. The Draper family has believed in and advocated for John's full participation and inclusion in all aspects of daily life since he was born. He was fully included throughout his school-aged years and always active in their community. Thus, it was a shock to deal with society's negative perceptions of people with disabilities at college and from the broader community. Nancy reflected:

> Sometimes the most difficult parts are dealing with the unexpected and being unprepared for emotions.

Finding creative ways of living is a Draper family mantra. John has become his own advocate, lodged a human rights complaint on his own behalf and begun to take on the education system about the importance of inclusion. Nancy believes he now sees part of his adult role as securing basic human rights for all people with disabilities.

It is difficult to adjust to adult services. Compared to the daily supports available in child service systems, supports for adults with

disabilities can be inadequate, ill informed or not available at all. Nancy reports this has been especially tough.

> It feels like you are led to the edge of a familiar place and then let go. Everything changes and the supports you once had are no longer available.

It is important to develop community-based social networks in high school. Nancy wishes now that everyone in the family had paid more attention to building John's social networks during high school. John agrees. "Social relationships are a real challenge. When people see me now, it's usually the chair, not the person they see. I don't know what to say or how to start a conversation when I first meet someone." As an adult who relies on AAC, John is finding it hard to make friends.

"Friends will be a big part of my life," he continued, agreeing wholeheartedly with his mother that the advice you get from your peers is sometimes more helpful than from your parents, particularly if it's about personal things. Nancy said she discovered early on that parents are not always the best ones to mentor and support their children as they reach adulthood. Also, getting advice from speech-language pathologists, educators, *etc.*, who are themselves part of the "older" generation, may be of limited value. Finally, she noted that counseling resources for adults with disabilities are sparse and that counselors are unfamiliar with the potential of people who rely on AAC and are inadequately trained to work with them.

AAC technologies play an important role, but planning for their use should be done carefully. John said, "It is important to consider how relevant AAC technology

> *It is important to consider how relevant AAC technology is to each environment. A system may work great in a clinical setting, but in high school and at college, it might not be appropriate.*

is to each environment. A system may work great in a clinical setting, but in high school and at college, it might not be appropriate." For example, he noted, "The voice output on my computer is not loud enough in some cases, and in others, it is way too loud." John concluded that while it is critical to have a good speech output device, it is also "important to realize that technology is not a miracle, and it won't solve all your communication needs."

Looking back, Nancy feels they should have been more realistic about the levels of independence John could achieve and then worked to develop both his low and high tech AAC systems accordingly. "We spent a lot of time learning to use a speech output device, and the truth is that he now uses it primarily for presentations." She also said that because it takes John a long time to type things, young college students sometimes haven't taken the time to listen.

Transitions can cause major financial concerns. John grew up in a family with an average income that was able to provide him with lots of opportunities for participation. As a disabled adult, he now gets some financial support from the provincial government. This includes a personal care attendant, but for only three hours a day, so the family pays for additional help.

"Being independent can often mean you have no quality of life," said Nancy. "When John moves out, he will essentially live in poverty."

Thus, one of his major goals is to find a full-time job. This is not easy for someone with severe physical and communication challenges. John said, "I have to think of creative ways to support myself."

Individuals with severe disabilities who rely on AAC and want to live independently as adults have to learn to negotiate a system that places them in poverty. Suddenly as an adult, your concerns may no longer be about quality of life or self-determination, but rather about survival. It's a "Catch 22" situation.

One must plan for the time when parents die or become disabled. Nancy said she is glad they have time to plan for this, but she also worries about whether community agencies will ever be prepared or have adequate resources. John said:

> This is a major concern because I will always need a backup plan for when something happens to my parents. I have a brother who would care for me, but I don't feel that this is entirely his responsibility. I must rely on extended family and friends. It's scary, but I am taking one step at a time.

It's frustrating to always be paving the way. Nancy pointed out that the parents who were advocates for inclusion, for AAC technologies, for equal education and literacy when their children were small, now find themselves having to begin anew, educating, training and advocating for adult services. Nancy concluded, "Professionals and the service system are simply unprepared."

The individual and the family must define success. John wrote:

> *Quality of life* for me means I am satisfied and reaching my goals. *Independence* means the ability to control my life, the ability to make choices for myself and the ability to accept the consequences for my

Finding My Voice: One Step at a Time
A Credo for Support

1995© Norman Kunc and Emma Van der Klift

Do Not see my disability as the problem.
Recognize that my disability is an attribute.

Do Not see my disability as a deficit.
It is you who see me as deviant and helpless.

Do Not try to fix me because I am not broken.
Support me. I can make my contribution
to the community in my way.

Do Not see me as your client. I am your fellow citizen.
See me as your neighbour. Remember,
none of us can be self-sufficient.

Do Not try to modify my behaviour.
Be still & listen. What you define as inappropriate
may be my attempt to communicate
with you in the only way I can.

Do Not try to change me, you have no right.
Help me learn what I want to know.

Do Not hide your uncertainty behind "professional" distance.
Be a person who listens, and does not take my
struggle away from me by trying to make it all better.

Do Not use theories and strategies on me.
Be with me. And when we struggle
with each other, let that give rise to self-reflection.

Do Not try to control me.
I have a right to my power as a person.
What you call non-compliance or manipulation may
actually be the only way I can exert some control over my life.

Do Not teach me to be obedient, submissive, and polite.
I need to feel entitled to say No if I am to protect myself.

Do Not be charitable towards me.
The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me
for their own gratification.

Do Not try to be my friend. I deserve more than that.
Get to know me. We may become friends.

Do Not help me, even if it does make you feel good.
Ask me if I need your help.
Let me show you how you can best assist me.

A Credo for Support, Continued

Do Not admire me. A desire to
live a full life
does not warrant adoration.
Respect me, for respect presumes
equity.

Do Not tell, correct, and lead.
Listen, Support, and Follow.

Do Not work on me.
Work with me.

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actions. A *self-fulfilling life* means that I am proud of my accomplishments.

He noted further, "I am in a big transition now because college is almost over and questions come up such as where do I want to work? What do I want to do in my field? Is it possible to live on my own?" Looking ahead ten years, he said:

I hope to be married and win the lottery! Seriously, two of my goals are to find accessible housing where 24-hour attendant care is provided and to work Monday through Friday at a job. Finding housing is discouraging because options are limited and the waiting list in Ontario is huge. Finding employment means I really have to focus on what I can do and what skills match a journalism diploma.

Conclusions. Nancy and John summed up their thoughts. Nancy made two suggestions for family members, professionals and individuals making this coming of age transition.

1. *Begin early*. Help individuals with complex communication needs and family members to start thinking and planning NOW.

2. *Talk honestly about expectations and realities*.

John's advice was to keep all options open, set expectations that can be reached and then plan

carefully. "It is important to have a Plan B in case something unexpected arises." He added:

I think professionals should have a vision for the future of each person they support.

In conclusion, John quoted Kunc and Van der Klift's *Credo*, "Don't solve our problems, help us solve them."

On the Web

Resources: Coming of age transition

There are many websites that discuss issues related to the coming of age transition. Very few, however, specifically address the needs of individuals who rely on AAC. Even so, here are a few I found interesting and useful. A Google search will bring you others.

Adult relationships, sexuality, crime, abuse

http://www.aacsafeguarding.ca/site_map.htm— This site, maintained by Augmentative Communication Community Partnerships-Canada has a wealth of information about issues related to the adult experience for individuals who rely on AAC. It offers a 44-page report about abuse issues and individuals who rely on AAC, including stories written about personal experiences. In addition, there are downloadable tools, including identification cards, over fifty sample picture and text communication displays, references and resources and articles. If you have Boardmaker™, the *Sexuality PCS Library* can be downloaded. There is also a link to information and guidelines about the justice

system for professionals and advocates [www.aacsafeguarding.ca/bestpractices-justicesystem.htm], and links to the symbol set LegalPix™. This site is a truly fabulous resource!

EU report and guidelines

http://www. european-agency.org/transit/index.html— The European Union held a conference on *Transition from School to Employment for Young People with Special Needs Education* in June 2002. This site offers a final report about problems, issues and options faced by disabled students in 16 European countries. The website contains a comprehensive Internet-based Transition Information database with comparative national information from participating countries. The site also gives policy guidelines at the national, regional and local levels and practical guidelines for educators and clinicians to facilitate the transition from school to employment for young people with disabilities. An informative site for individuals from any country.

Person-centered planning

http://www.capacityworks.com/index.html— This site highlights resources developed by Beth Mount on person-centered planning and "futures" planning. One resource is a book, *Information about Building New Worlds for Students with Disabilities in Transition from High School to Adult Life,* which describes the transition processes of students with disabilities and people who support them after graduation from high school. These students would typically land in highly restrictive adult day programs, but instead found opportunities in their communities through transition planning.

Parent resource center

http://www.asdk12.org/depts/SEPRC/disability/transition.asp— This site, maintained by the Anchorage school district, has links to articles about the transition to adult life, including links to sites on how to design Individualized Transition Plans (ITPs). The site is well organized and useful to both families and professionals.

Dare to Dream

The process called *Daring to Dream* evolved as a part of the Augmentative Communication and Empowerment Supports (ACES) Summer Institute at Temple University and has been used in various places around the world— most recently in Los Angeles with Dr. Diane Bryen as facilitator.

Daring to Dream is a complex process and a tool for building empowerment capacities. Too often, people with significant disabilities do what others want them to do. In a group situation, individuals work to make goals and plans for what they want in their lives and then gradually take action to make their dreams come true. The first steps are to think about their dreams (*e.g.*, where to reside, whether you want to marry, have children, spirituality, and so on). Facilitators encourage participants through a process that involves identifying dreams, planning for supports and resources and making action steps to realize their dreams. Though it may take years to achieve a dream, individuals are taught to take the first small steps towards realizing their dreams early in the process.

University & Research

Follow-Up Studies in AAC with Mary Hunt Berg

This article briefly reports on two comprehensive studies of individuals who received intensive AAC services as children and who are now young adults. Researchers compared earlier data with information collected at the time of follow up. In one study, Dr. Shelley Lund examined the long-term outcomes of a group of seven young men (ages 19-23 years) from Canada who have used AAC systems for at least 15 years.[18,19] In the second, Dr. Mary Hunt Berg studied the long-term outcomes of 16 students (ages 11-26 years) from the United States who had previously attended the Bridge School.[20,21] Participants in both studies have severe physical and speech impairments. More information is available from the researchers and in publications.[18-21]

Follow-up study of seven men after 15 years

For her doctoral dissertation, Lund measured the outcomes of seven young men with cerebral palsy across a broad range of domains including receptive language, reading comprehension, communicative interaction, functional communication, educational and vocational achievement, self-determination and quality of life. In addition, she conducted qualitative interviews with each participant to identify contextual factors that may have contributed to the measured outcomes.

Briefly, at follow up, two participants were still attending high school; two participants were in college; two were enrolled in adult life- skills training programs; and one had dropped out of school, was not employed and did not attend a day program. In receptive language areas (vocabulary, syntax and reading comprehension), participants scored well below the mean when compared to nondisabled peers. Only three participants could read and answer questions about paragraph-length material written at a first grade level. Their communicative interactions were multi-modal. All used body-based modes and a variety of AAC systems including low-tech, partner-assisted scanning, computers with communication software and AAC devices. Two individuals used direct selection, four used switches and one relied on partner-assisted scanning. While all had made progress in their turn-taking and other discourse skills since they were in preschool, three participants continued to rely on their partners to sustain interaction.

Three participants reported high levels of self-determination. Problem solving was an area of strength for four individuals and a weakness for two. Goal setting was an area of weakness for all but one participant. All obtained a high quality-of- life score, although they differed with regard to what contributed to their perceptions of quality of life.

During the interviews, participants identified barriers and supports that had influenced their lives.

Barriers. Cultural, technological and service delivery limitations, attitudes.

Supports. A supportive community, parent and family support, personal characteristics and appropriate and high-quality AAC services.

Outcomes of 16 former Bridge School students

During 2001and 2002, Dr. Hunt Berg examined the outcomes for 16 of the 33 former Bridge School students. Bridge School students temporarily leave their local schools to receive intensive intervention in the functional use of AAC strategies and technologies. After several years at Bridge, students return to their local schools to continue their education and achieve full participation in their communities. The Bridge School transition staff supports each student after discharge from Bridge by offering local educational teams a range of ongoing services.

As part of the follow-up study, researchers conducted retrospective analyses of archived educational records maintained at Bridge School, and held follow-up interviews with former Bridge School students and family members. They were able to collect complete data from seven males and nine females, ages 11 to 26 years. Eight (half) of the participants had returned to their school district one to four years earlier, and half had returned five to 12 years earlier (mean 5.5 years; range 1 to 12 years). At follow up, 13 were enrolled in their home districts (three in their last year of elementary schools, three in middle school and seven in high school). Eleven former students were in inclusive school settings and two were in special day classes. Of the remaining three, one student was in college; one was self employed and one was in a community immersion program. All lived at home with their families.

All participants in the study have severe speech and physical impairments, and seven also have visual impairments. At follow up, one participant had cognitive, language and literacy skills within the normal range. The others had mild to

moderate delays in cognitive and receptive language areas and moderate to severe delays in expressive language areas. Literacy skills were moderately impaired for four and severely impaired for 11 of the participants at follow up.

The retrospective review of archival records included a review of (1) IEPs, as well as associated documentation regarding use of assistive technology at Bridge, (2) professional reports, videotapes of interaction and team meeting notes generated at Bridge and (3) the IEPs, ITPs, IPPs, transition team contact logs and meeting notes generated after the participants returned to their home school. In addition, researchers conducted follow-up interviews using the *Social Networks Inventory* with each former student, a family member and a paid worker to collect data about communication partners, use of modes, assistive technologies, representational strategies, conversational strategies, topics, selection techniques and types of communication. Researchers also measured each individual's perceived quality of life[22] and self-determination.[23]

Results

Results revealed that former Bridge School students currently rely on a range of assistive technologies in their everyday lives. Fourteen use wheelchairs for mobility and two are ambulatory. Eight individuals are using switch-operated scanning arrays and eight rely on direct selection methods (four use iconic encoding) to operate their speech generating devices (SGDs). They all use body-based modes (facial expressions, body language, gestures, vocalizations) and a complex SGD. Seven also use a digitized device and seven use nonelectronic communication boards/books. Data also showed that

Table III. Level of participation over time

Social Participation				
	None	Involved	Active	Competitive
First Year	4	8	4	0
Last Year	0	2	13	1
Follow up	0	2	12	2
Academic Participaton				
First Year	8	3	5	0
Last Year	0	2	13	1
Follow up	0	2	11	1

participants use body-based modes more frequently than aided modes.

Analyses of archived educational records at Bridge indicated that complex SGDs were explicitly targeted as an educational goal for all but one student in the study. When students left Bridge school, four were independent in their use of an SGD after someone set them up, while all others required assistance. At follow up, one former student was completely independent (*i.e.*, required no assistance with set up), while the others remained at levels reached during their enrollment at Bridge School.

By framing archival data from educational documents and team meeting notes using Beukelman and Mirenda's Participation Model, researchers looked at the former and current levels of participation for each former student. Table III shows a retrospective review of IEP goal
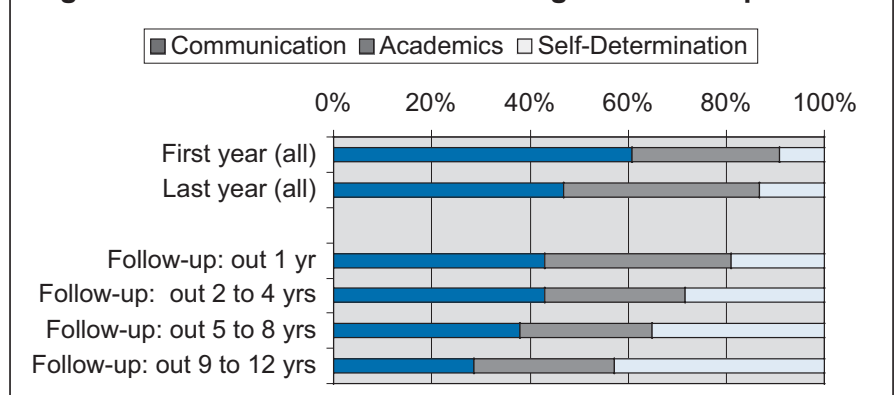
categories. During the students' first year at Bridge School, expectations for social participation were higher than for academic participation. During the students' last year at Bridge, social and academic participation goals were comparable. In year one, the students' levels of participation were low compared to when they left. This trend of increasing participation continued after leaving Bridge.

Figure 1 shows that the focus of instruction also shifted. Initially, the emphasis was on developing communicative competence, but goals gradually expanded to include the development of skills in academics and self-determination as well. After leaving Bridge School, the focus on academics and communicative competence diminished, while goals emphasizing self-determination gradually increased.

Quality of life is based on a person's subjective interpretations of life's possibilities and experiences, including personal well-being, life conditions and perceptions of others. Quality of life measures at follow up indicated that former students of Bridge perceived their quality of life as positive. As expected, their perceptions of what contributed to their high quality of life varied.

For the most part, the 16 partici-

Figure 1. Focus of Instruction at Bridge & Follow-up

■ Communication ■ Academics ▢ Self-Determination

First year (all)
Last year (all)
Follow-up: out 1 yr
Follow-up: out 2 to 4 yrs
Follow-up: out 5 to 8 yrs
Follow-up: out 9 to 12 yrs

pants had circles of communication partners (CCP) that were full and balanced. All reported that their primary communication partner was a close family member, usually a parent (circle one). Thirteen former students also reported someone in their first circle was the person they spent the most time with, the most skilled partner and the person most willing to teach others communication strategies. More than half (9) cited a family member as their favorite communication partner, while five named a friend and two named a paid caregiver. Paid workers were never named as primary communication partners, but were sometimes cited as most willing to learn or most willing to teach others to communicate with the participant. Only one participant accepted major responsibility for training communication partners. Acquaintances were sometimes identified as persons willing to learn new skills.

In analyzing data related to friendships (circle two), 14 former students reported they had same-age peer friendships. Most were close relatives (*e.g.*, cousins) or the children of parents' friends. Occasionally a participant listed a former paid worker as a friend. Interestingly, those with the most same-age peer friendships had brothers and sisters still living at home.

The findings suggest that families and their social networks played a major role in the development and maintenance of the participants' social networks. Many communication partners were family friends. However, it was also noted that older participants had the highest number of peer friendships, suggesting that over time these individuals developed relationships apart from the family. In any case, former

Bridge students report opportunities to interact with a range of people and are using a range of tools, devices and strategies to do so.

Summary

These two follow-up studies report on the outcomes of individuals who received intensive AAC services as young children. In both studies, participants were using a variety of AAC technologies and strategies. Some, but very few, had become functionally literate. All continued to have significant physical, cognitive and linguistic challenges. Even so, all report a positive quality of life. Although these data do not reveal why certain outcomes occurred, both studies are instructive and underscore the need for researchers to conduct longitudinal studies that can better account for future outcomes.

Equipment

Transitions: Straight Talk by Johana Schwartz

I would like you to think about how it feels to go through a transition. And, what your life is like if you avoid change. I have gone through a number of recent transitions. I transitioned from using one AAC device to another. I also transitioned from being a student going to school, to being an employee working at a job. My latest transition is from living at home with my parents to living in a facility where I am learning independent living skills. Soon I will be living more or less independently in a communal residence with others who have disabilities. All this is a lot to take in at one time.

Transitions are inevitable. We all face them at points in our lives, or life could become pretty boring. They happen at different times for different people. How we handle change matters, no matter when the transition occurs. The key to making it through a transition is courage and perseverance. I like to remember the song:

*Make new friends, but keep the old.
Some are silver, and the others gold.*

What this means is, when we leave something behind to move on to something new, we will take some of our old skills and habits with us and keep using them. Maintaining contact with friends and family helps ease any transition. But we may lose or have to drop some of the skills, habits and people we are comfortable with. A transition can be a trade up, and is often a risk. We have to keep in mind that we may lose things we like, but we most certainly gain new and better opportunities. We have to balance being comfortable and being good at the familiar with being flexible and open minded about trying new skills and living differently.

Technology

I depend upon technology to do many things. I use an AAC device, an electric wheelchair and a computer. Access is a challenge for me and so is compatibility between my various technologies. I use a head mouse to access my device, an infrared relay to operate my computer and a head control array to drive my power chair. When I moved, I brought my laptop and wheelchair with me, but I changed my AAC device, which brought new challenges. The day I discovered my new AAC device at my front door, I saw it as a black box…something I had to spend time exploring in order

to discover its secrets. I practiced it with perseverance, making it my priority to become proficient. I no longer had an IEP or a speech-language pathologist who could train me. I had to be responsible for learning to use it and had to find out what it could, or could not, do for me.

While exploring my new device, I found some features I liked better than what my old one offered. Others were disappointments. Initially, it was hard to communicate anything at all because my favorite shortcuts had disappeared. The interface with my computer was not as smooth as with my previous device. On the other hand, the new device came with advantages and improvements that were very useful in my new job. For example, I have made a few public speaking appearances. I was able to more easily change voices, so when I quoted what other people had to say, it was clear who said what about the subject.

Because I want to live independently, I like the environmental controls in my new AAC device. They allow me to turn on the lights and other appliances by myself. I can also adjust the speaker volume in my device on my own. This means that I can start talking to you whenever I like or whenever I am ready. It feels very liberating to be in control of these things.

Unfortunately, at the place where I went to learn new independent living skills, not everyone was well informed about assistive technology. As a result, maintaining the level of independence I had before I enrolled became a challenge. Recently, my lap top computer was stolen, with huge repercussions for my growing independence. My ability to work, manage my personal affairs and play

is seriously compromised. Writing, Internet research, email communication, managing my calendar and my "to do" list, accessing my address book, reading books I have downloaded and listening to music are all impossible for me without a personal computer hooked up to my access technology. My goals for independence that I had identified in my independent living program all revolve around the use of my personal computer.

Making change work

Identifying and acknowledging the pros and cons of change help in making decisions about our lives. When I know the cons, I can look for ways to remedy them and look for resources to help. I always try to find people who have already made the same transition I am about to make. People like to help each other. I ask questions like, "What worked for you?" I also volunteer strategies that have worked for me.

One place I have turned to for support is the ACOLUG listserv for people who use communication devices. On ACOLUG, I have met other people who had already mastered my new device and could answer my questions over email.

Final thoughts

The important thing to remember is that others before us have made the same transitions we are facing. In the middle of a transition, it is normal to feel adrift. However, when we are able to identify advantages and gains that come from making changes, then we are acknowledging that our life has improved and we have grown from the experience. As the author Erica Jong said:

Thank God there are people who are capable of change. And they're always a minority—but then it's always been a minority that changes the world.[24]

Resources

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