Supporting Transitions to the Adult World for Individuals who use AAC
David McNaughton

(Slide 1) Hello, my name is David McNaughton and over the next few minutes I will be talking about strategies for supporting successful transitions for individuals who use augmentative and alternative communication. I'll be talking about some of the research that we have done here at Penn State: research looking at outcomes for individuals who use AAC; research looking at ways to support employment for individuals who use AAC; I'll also be talking about some of the research that we have done on mentor programs for individuals who use AAC and teaching communication skills. So, I hope you enjoy this presentation on supporting successful transitions for individuals who use AAC and thank you for the opportunity to share this information with you.

(Slide 2) One of the first questions is what are some of the key components of a successful transition? For some individuals, success in transition might be measured by the fact of whether they have a job or not. For other individuals it might have to do with how many people they know or how rich is their social network. For other individuals success might be measured by whether they are able to start a family or have been involved in starting a family. Again, for other individuals it might be the extent which they participate in recreational activities and have close friends.

(Slide 3) One way of looking at and learning more about transition experiences for individuals who use AAC is to look at the long-term outcomes for individuals who use augmentative and alternative communication. Lund and Light in a study in 2001 did an outcome study to measure the impact of augmentative communication interventions in a variety of domains so they looked at outcomes for 7 young men in a wide variety of areas: language development, literacy skills, educational status, their satisfaction of life, their levels of self determination in a wide variety of measures. These 7 young men had originally participated when they were preschoolers in a study that Light, Collier, and Parnes did in 1985. All these individuals had a diagnosis of Cerebral Palsy; all were between the ages of 19 and 23, all of these individuals had significant speech impairments and had used augmentative alternative communication for at least 15 years. At the time of a follow-up study in 2001, these individuals used a variety of augmentative systems to communicate. So, some used high-tech computer-based augmentative communication systems, others used low-tech communication boards; many used a combination of both high-tech and low-tech.

(Slide 4) One of the interesting outcomes for this group was to look at their educational status and vocational achievement. Two of the participants were still in high school, one was in an academically competitive program. Two of the participants were attending college. Two participants were enrolled in a life skills program. One participant had dropped out of school in the 10th grade and was not employed or involved in a day program.

(Slide 5) All of the participants reported a positive quality of life, but there was significant variation as to the quality reported. Interestingly, participants differed with regards to what domains contributed to their quality of life, so participants differed with respect to what was the most significant contributant to their perceived quality of life.

(Slide 6) One interesting way to look at the results is to start to look on an individual basis and the levels of satisfaction reported. Leo was a young man who was unable to read at a grade 1 level, had dropped out of high school in the 10th grade, but reported high levels of self-determination, so on measures of self-determination Leo reported that he was able to gather the information that he needed, make decisions and follow through on the decisions that he had made. He reported a high quality of life. Josh, another participant was able to read at the 6th grade level and was at the time of the study academically competitive in a high school setting, but Josh was not satisfied with his quality of life.

(Slide 7) What becomes clear when we start to look at individual outcomes is that the interpretation of transition outcomes and people's satisfaction with them very much depends on the perspective of that individual. So to the extent that people have different goals, different values and priorities, different expectations, people are going to report varying levels of satisfaction with their transition outcomes.

(Slide 8) What is true across all of these individuals though were the factors associated with a high quality of life. So what was true for all of the individuals that reported a high quality of life was high levels of self-esteem, so these were individuals that felt good about themselves and their personal achievements, strong levels of self determination, so these were individuals that felt they were in a good position to gather the information that they needed, make decisions and they would then be able to follow through on those decisions, and also strong social networks and relationships, so these were individuals that were very satisfied with the number of people that they knew and their social network.

(Slide 9) One important area for individuals as they look at transition outcomes is that of employment. Over the past few years we've had an opportunity to learn more about employment for individuals who use AAC. Some of it is good news, and some of it better defines the challenges that we face. At present, over 85% of individuals who use augmentative and alternative communication are unemployed. Employment barriers include lack of education and job preparation, transportation and work place supports and barriers, and also attitudinal barriers.

(Slide 10) When we look at it from a more positive angle so to speak and look at who is working we see that individuals with a range of abilities and disabilities are currently employed. So we see that there are individuals with Cerebral Palsy who use augmentative and alternative communication who are employed, we see individuals with mental retardation who use AAC who are employed and also we are finding individuals with autism who use AAC who are employed.

(Slide 11) When we look at the type of job that they are involved with, we see that they are involved in a variety of capacities. We see individuals who use AAC involved in clerical work, working as laborers, some are involved in the public education system in classrooms, some are involved as educators either out in the community doing trainings or working in post-secondary institutions, some individuals are technology consultants and technology support staff. We also see individuals who use augmentative and alternative communication employed as writers, artists and musicians.

I'd like to share 2 clips of 2 individuals who use augmentative and alternative communication participating in work place activities. In the first clip we will see Larry doing a workshop presentation.
{Video}

I really enjoy that clip because to me I think it illustrates the widest variety of alternative communication modes I've ever seen. You've got Larry using a lap top computer, his presentation is being translated into sign language and at the same time it is also simultaneously being translated into Spanish. In our second clip, we will see Paul, a young man with autism, working as a bagger at a grocery store. If you listen carefully, you'll hear him make use of a small portable voice output aid attached to his hip to thank the customer for using that particular grocery store.
{Video}

What I find interesting about Paul's experience in the grocery store is at first the manger of that store had been reluctant to hire him until the work support staff that worked with Paul were able to demonstrate that not only was he the only bagger that consistently showed up on time, but he was in fact one of the most efficient baggers because he was very concerned about things being done properly and being done in an orderly way, so he turned out to be a very satisfactory, very positive hire for that grocery store.

(Slide 12) One interesting way to look at this issue is to think about what are the factors that need to be in place in order to see employment success for individuals who use AAC, so in a sense what does it take to make it work. Over time through our research there have been three factors that have proven to be very important. The first is marketable skills, the second is effective communication skills including networking skills, and the third is a strong work ethic, individuals who use AAC have a very high work ethic and this would also cover time management skills. I am going to look at each of those in just a little more detail.

(Slide 13) With respect to marketable skills, there are three areas that are important there. First, the formal educational experiences of the individual, their literacy skills and also their informal educational and work or volunteer experiences.

(Slide 14) In one of our past research projects, we did a survey of individuals who used AAC and were employed, and there were a number of things we found out about their educational experiences. First, roughly half of the individuals who used AAC and were employed had at least a high school diploma. So one of the things this tells us is that it's

very helpful to have as high as possible in terms of formal education or as many as possible formal education experiences in terms of seeking employment. The other side of the coin though is it's not absolutely necessary to have a high school diploma in order to find employment. The one sort of warning there is that for those individuals who used AAC and were employed the ones that had a high school diploma or better had more job options and were more satisfied with their jobs. The individuals who did not have a high school diploma and were employed also tended to be the individuals with the less severe disabilities. For individuals with more severe physical disabilities, it really was important to have at least a high school diploma. Many of the jobs that those individuals did were computer based, and strong levels of formal education were very important for those individuals.

(Slide 15) When we look at the literacy skills of the individuals who used AAC and were employed, again, strong levels of literacy were reported by those individuals who were most satisfied with their jobs and those individuals who felt they had the greatest chance for promotion. There were individuals who used augmentative communication and who were employed that did not have strong literacy skills, but again these tended to be the individuals with less severe physical disabilities involved in labor type activities, these tended to be the individuals that weren't as satisfied with their jobs, and who did not feel they had the same opportunities for advancement as did those individuals with stronger literacy skills.

(Slide 16) One of the many challenges that individuals who use AAC report that they face in seeking stronger educational skills, are their low expectations and the lack of knowledge about AAC that they sometimes encounter in the school system. One of the individuals that participated in our study said, *"We were taught half or less of what other kids were learning because at that time it was believed that we couldn't understand as much."* Another individual who used AAC reported, *"I didn't use all of the AAC devices I got before at school because no one taught me how to use them."* So again, low expectations and lack of knowledge about AAC served as major barriers for some individuals who use AAC in trying to develop their literacy skills and their educational status.

(Slide 17) Also described as very important to possible employment outcomes were informal educational experiences. So, many of the individuals who had gained employment recorded that past volunteer activities - so working with a classroom aide, working as a writer for a non-profit magazine, working as a presenter for an assistive technology firm - all of these informal educational experiences had helped them both build their job skills, extend their job contacts, so got them in touch with a greater variety of people that helped with pursuing other job opportunities and also helped them in developing their resume, so that when they did apply for jobs, they were able to provide evidence of their participation in the work place.

(Slide 18) One of their participants reported, *"The way I got started was by volunteering at a local school, that's when someone noticed me and my abilities."* There is sometimes a thin line for participating in volunteer activities for individuals who use AAC. The

individual who uses AAC in a sense needs to volunteer long enough that someone recognizes their competence, but needs to be careful not to volunteer for so long that others, particularly the employer, feels they have got a free worker who doesn't need to be paid. Some other people who use AAC that participated in our study suggested the best thing to do was to participate for a short period of time in order to demonstrate competence and then to sit down with the employer and really try and get a better sense of where the employer saw it going and seeing if it would be possible to map out some sort of plan towards paid employment.

(Slide 19) The individuals who are employed and participated in our survey as employed individuals who use AAC encountered a wide variety of assistive technologies to support augmentative communication. Luckily _ of the individuals who were employed and who used AAC reported having a portable voice output communication aide, but as you can see, the individuals who have employment make use of a variety of modes of communication. Over half still use speech or some kind of speech approximation, roughly a third use gestures and signs, and roughly a third have an alphabet or a word board. As you can see, many of these modes were used in combination, so people made decisions about which mode would be most effective in a particular situation. People also placed great important on having a back-up mode, so they had an alphabet or word board ready in case the portable voice output communication aide broke down.

(Slide 20) The issue of having a back-up to the AAC system is something that was stressed by some of the employers of individuals who use AAC that we spoke with in our research. One of the employers of an individual who uses AAC said, *"we know para-transit is not going to show up and we know that personal assistants are not going to show up and we know your device is going to break. So, what's your back up to that? If someone is going to do a presentation to one of our classes on assistive technology, I don't want the excuse 'oh gee, the device broke.' Have a back-up."* These are the realities and they will happen, so clearly the expectation of the employer is that the individual who uses AAC be prepared for the technology breakdowns that we all hope aren't going to happen but often do.

(Slide 21) The individuals who used AAC who were employed also presented with effective communication skills and this wasn't so much an issue just of how quickly they could use their device or the size of vocabulary contained in their device, although these factors were important, an equally important factor was their ability to establish and maintain positive social interactions. One of the augmentative communication users who participated in our study had this suggestion for individuals who use AAC and who were pursuing employment, *"They, the AAC user, must start a conversation with the interviewer right from the beginning. Because, you might be the first augmentative communication user that the interviewer has ever seen. By starting a conversation, you will make the interviewer comfortable and show them how intelligent you are."*

(Slide 22) Another key factor for employment success for individuals who use AAC was strong social networks, and this plays out in a couple of different ways. First, individuals who use AAC need to work to establish and maintain strong ties with family, close

friends, people that know them well. These can be important leads in pursing employment. As important as the strong ties though are weak ties, so the extent to which an individual who uses AAC is known by and known to, maybe people that aren't quite as close, but people who might be helpful in helping that individual find the job. So to the extent that an individual who uses AAC has gone to school with other students without disabilities, in a sense that other class could be identified as people that have in a sense weak ties to the individual who uses AAC. They are familiar with him, they could be made aware that he's looking for a job, they may have an important role to play in helping that person find employment. The reason that it is important to think about social networks is when we look at those individuals who use AAC and who are employed, it becomes clear that pull can be as important as push and what I mean by that is to the extent that an employer is actively looking to recruit and hire a particular individual who uses AAC, that could have a far more positive effect, or a very positive effect on employment outcomes and that can be just as important as push in a sense, push here being the idea of how much the individual AAC wants the job. So I guess what I am arguing for here is sort of a balanced approach while at the same time push is very important, so it is very important that the individual who uses AAC really wants a job and is looking to find a job, pull can also be important as well, so trying to think of situations where employers may have an active interest in hiring an individual who uses AAC or an employer might have some special benefit that could be obtained by hiring an individual who uses AAC and we'll talk about some of those areas in just a few minutes.

(Slide 23) This idea of strong ties or weak ties and the importance of pull is illustrated by this overhead, which describes what we learned about how individuals who use AAC actually found their job and you'll notice there that family members and friends and professionals - so teachers, speech language people, individuals that had worked with the individual who uses AAC make up almost _ of the job leads reported by individuals who use AAC. So family members and friends and professionals combined make up the largest group of important leads for individuals who use AAC and who are seeking employment.

(Slide 24) The importance of personal support networks was illustrated in this quote from an individual who uses AAC, *"I was taught that you need to work hard to get where you want, yet you must be careful that you don't step on other people's toes. It's all about networking and working hard."* So in a sense what this person is recognizing is the importance again of both pull and push, getting to know a lot of people and hopefully getting them interested in getting you employed and at the same time being willing to work hard to pursue one's goals.

(Slide 25) Finally another very important issue for individuals who use AAC is that they demonstrate a strong work ethic. This includes both time management skills, as one individual said, *"we don't have the luxury of being spontaneous everything needs to be extremely well planned out in terms of personal care, transportation, how work activities are going to be arranged."* The other important issue to consider when thinking about a strong work ethic is that the individual who uses AAC really has a good understanding of the positive and the negative aspects of employment.

(Slide 26) When we look at the positive aspects of employment one of the important positive aspects of employment reported to us by individuals who use AAC is that of feeling productive – there are a couple of things associated with this. One is that they reported that they liked changing the public's perception about what individuals who use AAC could do, so one of the individuals who participated in one of our studies said, *"I like proving everybody wrong, it does work because they learn from us, they remember too."* So an important part of being employed for this individual was the opportunity to show the larger community what individuals who use augmentative communication could achieve.

(Slide 27) Another positive aspect of employment was the positive experience of being out in the workplace. So the fact that some of these individuals very much enjoyed the work that they did and enjoyed the opportunity to interact with people at work. One individual said, *"I enjoy working and being out in the workplace, contributing, making new friends, etc"*

(Slide 28) Another positive aspect for employment reported by individuals who use AAC was that of meeting personal goals that they had set for themselves. One of the individuals who participated in the study had this to say about employment, *"Yes I have disabilities; however it does not mean I am not a human being – why did I go to school? Why does anybody go to school? It is to learn, me too. If I did not go to school and did not want to work, what is the difference between a dog and me? Last time I checked I was still a human being."* I think it's important to note here this individual is not saying that if he didn't have a job, he would be a dog, I think what this individual is saying here is that what makes him a human, or what makes him who he is, is the fact that he wants to be as involved as he can be, so he wants to go to school, he wants to do work, he wants to do all the things that he can, and to him that makes him the person that he is.

(Slide 29) While it's important to have a good understanding of the positive aspects of employment, I think it's equally important to have an understanding of the negative aspects of employment and these are some of the negative aspects that have been reported to us in our research on people who use AAC who are employed. The first aspect to consider is the impact of full-time employment on physical and mental health. A number of individuals have talked to us about the difficulty of, you know, adjusting to the daily grind, their dissatisfaction with the job, and sometimes dealing with difficult with feedback. As one individual said, *"working all day is not easy, but I knew that already. I didn't say anything about it at my job - either I make it or I don't."* So one of the things that is sometimes challenging for individuals who use AAC is they are reluctant to talk about things that could be done to make their job easier because they don't want to be seen as not being competent or able to handle the responsibilities. Another individual said, *"it isn't work that's difficult, it's just boring and dry."* So for this individual, there was a trade-off between an interest in employment and the need to take at least for the time being a job that wasn't seen as terribly exciting.

(slide 30) Another negative aspect of employment is the impact of work on non-employment activities. So, work was sometimes so challenging that it had an impact on the non-employment activities of an individual. One individual who used AAC commented, *"I think the biggest challenge with having a full-time job is balancing everything in your life, making sure the things like shopping and cleaning get done in a timely manner."* Another individual who uses AAC and was employed said, *"I also had to make sure I had time to take care of me. For example, making sure I made time to be sociable and go to movies, or just hanging out with friends."*

(Slide 31) Another negative aspect of employment was sometimes the financial issues or the financial challenges associated with employment. For individuals who were on government aid, it was sometimes complicated to figure out how much they could earn and what the implications of earned salary was for government supports. One individual commented, *"I'm on government support and can make up to $700 a month, but you have to be careful."* This was seen as a confusing, complex area for individuals who use AAC and again they were very cautious or very concerned about how much money they could earn before it would have a negative impact on government benefits.

(Slide 32) Out of the key supports that are necessary, that have been found to be important, for individuals who use AAC as they pursue employment come some recommendations for family, friends, and educators. There are three that I would just like to talk about for a moment or two. The first is to support the development of employment skill, the second is to build communication and social skills and the third is to try and develop the social network of the individuals who use AAC.

(Slide 33) With respect to supporting the development of employment skills, I think we can look at this quite broadly. One way to think about it is to think about what are the ways that we can encourage individuals to take personal responsibility from an early age. Faith Carlson does that in a presentation called "How are you going to get a job if you don't start when you are 6?" which I think is kind of a fun way of looking at things and I think the message there is that from a very early age we need to be involving people who use AAC in situations where they are making decisions, making plans, providing directions to others, following through on commitments. Sometimes in school environments, individuals who use AAC can be growing up in situations where there are things that are done for them and they're never really put in a position of trying to give instructions to others and yet if you think of the kind of skills they're going to need in the work place, managing personal care attendants, working with other employers, it may be useful for us to try and think from a very early age where can we help those individuals to get those opportunities while they are still in school.

(Slide 34) Sometimes however those skills alone are not going to be enough, and this is where a person's ability to solve problems and think creatively is going to be important. One individual that participated in our studies had a teaching certificate but still could not get a job from a school district and in the end it was necessary for that individual to threaten to sue the school district before he actually could get hired. It was necessary to involve the threat of the legal action to get the schools to recognize that this person was a

qualified and certified teacher. So, this individual's advice was, *"you must have a good lawyer in order to get a job. For my job it took me about 2 years to get my job. Don't give up!"*

(Slide 35) Another way that parents and educators can help individuals who use AAC develop skills they need for employment is to work in developing their communication skills and social confidence. One of the things we heard from employers was that they like positive, upbeat people in the workplace and they found that in hiring individuals who use AAC, they had really been able to effect a very positive change in their workplace. One employer reported, *"after we hired Greg, who was an individual who used AAC, no one complained about having a cold or not being able to find a parking space."* So hiring an individual who used AAC had had a very positive effect on office morale.

(Slide 36) A third way that parents and educators can help individuals who use AAC prepare for employment is to help them develop their social network. There are a couple pieces to this; one is to help them keep their strong ties strong, so to encourage them to keep in touch with former teachers, therapists, extended family members – it is hard to know, you know, where a good job lead is going to come from and basically you want to make sure that those individuals have the individual who uses AAC in mind as they look at and are in touch with different job opportunities. A second way to develop the social network is try to develop new weak ties in a sense, so look for ways to reach out and meet with people that may start as weak ties and hopefully over time will become strong ties. So, things like presenting at conferences, joining service groups, perhaps getting involved in electronic networking, becoming involved in some of the list serves for individuals who use AAC and list serves for individuals who have an interest in people who use AAC like ACOLUG, all are ways to reach out and establish new ties that as I said hopefully over time will become stronger ties.

(Slide 37) Another way to introduce yourself to other people is through the use of web pages. As one of our individuals who was employed commented, *"a web page can be a powerful tool to break the ice before an interview and they will know what to expect when they first meet you."* This particular individual in getting a job would send out his resume to companies that he thought would be interested in someone with his work skills, but when he sent out his resume, he did not provide information on his disability status, he did not provide them with information that he used AAC. When the hiring process had gotten to a stage where he was being scheduled for an interview, at that point he informed the hiring company that he had a disability and used AAC and at that point he directed them to his web page, where he had information on how he had participated in the work place in the past and how he looked after issues of operating a computer and transportation and personal care attendants, so he followed almost a two-step process there, where the web page served to provide more detailed information about his skills and how he managed in the work place after he had first gotten the employer interested by using his resume that listed the skills and the competencies that he would bring to that employer.

(Slide 38) This issue of developing weak ties is clearly a challenging one, but in working to develop new ties for yourself, it's important to realize that as individuals who use AAC do that, they're also performing a very valuable role in terms of changing society's perception of individuals who use AAC generally. Michael Williams, an individual who uses AAC, has commented that, *"every time you as an individual who uses AAC step out of your home, cruise down the street, catch the eye of a stranger, make a purchase, attend a ball game, say hello to a child, you are making a significant change in the expectations the world has of augmentative communicators. Living your life out and loud is a contribution to society."* Thirty years ago we rarely saw individuals who use AAC in the community. As we work to change societal attitudes toward individuals who have disabilities and individuals who use augmentative communication, the impact of simply being out in the community, as Michael says, living your life out and loud, can have a powerful impact on societal attitudes.

(Slide 39) We've talked about the important factors for the individual who uses AAC and the things that educators can do and family members can do to help support the develop of work skills by individuals who use AAC. Another area to think about is what does it take to make it work from the perspective of the workplace and society?
A number of factors to consider here first is the fact that we have a knowledgeable employer, second is that there is an appropriate match between the client and the job, third is an efficient and effective assistive technology, fourth is access to transportation and fifth that there is a positive and effective support network, including personal care attendant services. I am going to talk about each of those in a little more detail.

(Slide 40) With respect to knowledgeable employers, I'm happy to report that in the research that we did where we spoke to employers about the individual with AAC whom they had hired, all of them reported that individuals who used AAC were skilled, loyal and hardworking. So we have a very positive message that we can share with potential employers. One of the employers said in describing their employee who used AAC, *"he needed to be somewhere the next morning and we had been having trouble with para-transit, which had often been a problem. He slept on the floor here at the office so he could be here on time. So, the motivation was extraordinary and you have to respect that."* Again, we should not be living in a world where people have to sleep on the floor in order to be at the office on time, but I think this just speaks of the dedication to many individuals who use AAC and the loyalty that they feel to their job.

(Slide 41) Another important factor is to try and identify an appropriate match between a client and the skills of that individual and the job. Again one of the employers who had hired an individual who uses AAC to help with compliance violations by employers, in describing the work of this individual who uses AAC, the employer said, *"he knows the laws and regulations related to disability rights and does very well at contacting non-compliant entities and advocating with them to become compliant."* And again, this is probably a situation where an individual who uses AAC may in fact be more powerful than an individual without disabilities in this kind of situation – you know, in terms of following up with employers that are non-compliant you have to think that needing to work with an individual who has a disability themself is going to carry some weight and

the employer who is not following the regulations probably realizes he does not have a lot of wriggle room in terms of disability rights in working with an individual who uses AAC themselves.

(Slide 42) Another important contributing factor to positive workplace outcomes are efficient and effective assistive technology. A couple of issues to consider here. First, the speed with which the individual is able to operate the device - often helpful to look at workplace vocabulary and the kinds of words or phrases that that individual may need to frequently use, to think about ways of pre-programing them in the device so they are easily accessible. Second, that there is some way of dealing with breakdowns in the workplace. Third, and this perhaps isn't really a technology issue though ideally over time hopefully we will be able to develop technology that will be better able to assist us in this area, the reluctance of some co-workers to socialize. Many individual who use AAC try to approach this by developing multiple modes of communication, using some modes in some situations, so perhaps, you know, a letter and an alphabet board with a highly familiar partner because that was quicker and using computer based high technology systems that perhaps were a little bit slower but had clear output for unfamiliar coworkers.

(Slide 43) Another important factor identified by individuals who use AAC was access to transportation. As one individual who uses AAC said *"don't take me to Baghdad first,"* I think this is in reference to the fact that for many individuals para-transit makes a number of stops before taking an individual to his or her desired location and this makes it very difficult for individuals to plan their workday or at least when they are going to be arriving at work. We've been starting to investigate telework, the idea that an individual would work from home and in a sense tele-commute or use the internet to communicate with people in the workplace as one potential solution to the problems of transportation that are frequently recorded. As we investigate that area though we need to really think carefully about while clearly there might be some advantages to telework, so the fact that we don't have to deal with transportation, we need also to think very carefully about what might be some of the disadvantages to telework, so, are we losing opportunities for social interaction for example when an individual chooses to work from home rather than actually participating in the workplace.

(Slide 44) Another important factor to successful employment outcomes is the support network of the individual who use AAC. Important factors here include the personal care attendant and the fact that that individual is on time and ready to work, training in workplace culture, so for many individuals who use AAC their first job following graduation, whether it is leaving high school or college is the first job they have ever had. There are a lot of little subtle issues associated with workplace culture that are difficult to pick up in an individual's first job, many of us probably learnt things on our first summer job, like how to look busy when the boss turns around, sort of thing, that we all pick up over time, so it's that knowledge of workplace culture that is important for individuals who use AAC and something that many individuals record as helpful was to look for volunteer opportunities whilst still in school as a way to try and develop a better understanding of workplace culture whilst still in school and before graduation. Finally,

in terms of a support network, it's also interesting to think about the role of the employer. Many of the individuals who used AAC and who were employed reported that their employer often fulfilled a valuable role in terms of modeling appropriate communication skills and attitudes. So co-workers often picked up on the skills and the attitude of the employer or boss towards the individual who uses AAC and that was an important part of the support network reported by the individual who used AAC.

(Slide 45) So just in looking at employment, I like this quote by Ochocka, Roth & Lord, it's actually from the study describing workplace experiences for individuals with a variety of disabilities, but I think it holds true for the research that we have done on employment for individuals who use AAC. *"The key accommodation to successful employment was an attitude among co-workers and employers that it was important to pay attention to the individuals' needs…and to accept accommodations as a natural part of the work experience."* So those most successful employment situations were ones where the employer realized that everybody in the work place is going to have some kind of special needs or everybody in the workplace is going to be in need of some kind of accommodation. The accommodations of an individual who uses AAC may be different from accommodations needed by other people, but there is a need to accept accommodations as a natural part of the work experience.

(Slide 46) So again, we've been talking about factors associated with a high quality of life, issues of high self-esteem, strong levels of self-determination, and strong social networks and relationships. We've looked at how some of these factors are associated with employment, but there are others ways of pursuing these factors aside from employment, and that's what we're going to talk about next.

(Slide 47) While employment can be one way that individuals pursue factors associated with a high quality of life so high self esteem, for example, we need to be careful that we don't treat it as the only way that individuals can pursue a high quality of life and that we think of a variety of ways in which individuals can be involved in activities that provide high levels of self esteem, provide them with strong social networks, and also give them opportunities to make and act on decisions. One activity that we've been involved with here in Penn State that pursued those goals was the Mentor Project.

(Slide 48) The Mentor Project started from the idea that there is a variety of challenges for people who use augmentative and alternative communication and that some of the things that we want to try and achieve for individuals who use AAC is to provide them with opportunities to maximize their educational and vocational achievement, participate fully in society, pursue meaningful goals, and enjoy a high quality of life.

(Slide 49) As we think about those, I think it becomes clear that as we look for supports to achieving those goals, we realize that encouragement from relevant role models, well-developed problem solving strategies, and access to information all serve as important supports for individuals who use AAC achieving desired outcomes.

(Slide 50) At the same time we realize that very often it's individuals with disabilities who may be in the best position to help other individuals with disabilities achieve desired outcomes. So as Bowe, Fay, and Finch suggested, *"disabled individuals with several years of disability experience are frequently better aware of the needs of disabled people and better informed about government benefits than our able-bodied professionals in the rehabilitation delivery system."* So if our goal is to try and think of a way that we can link up individuals with disabilities with other individuals with disabilities, one model to think about is trying to set up in support people a mentor relationship.

(Slide 51) So, mentors have been defined in a couple of different ways. One definition for a mentor is that a mentor provides a brain to pick, a shoulder to cry on, and sometimes a kick in the pants.

(Slide 52) So, with this in mind, we started the AAC Mentor Project, and it had 2 components. The first was leadership training that took place over the worldwide web, and our goal there was to develop the skills of individuals who use AAC to act as effective mentors and to try and build in a sense leadership capacity among those individuals. The second piece of the project was to working with those individuals who have received leadership training and match them up with adolescents and young adults who used AAC so that the older individuals who use AAC and have been trained as mentors could help those individuals in solving problems and in meeting personal goals. The interactions between the mentors and the protégés, that is the adolescents and young adults who used AAC, took place via e-mail.

(Slide 53) So, we had 31 adults who had a diagnosis of Cerebral Palsy and used AAC participate in the leadership training project. All those individuals demonstrated functional literacy skills, all those individuals had achieved some significant goals in their lives, so they were either living independently or were pursing secondary education or employment of some kind and all those individuals demonstrated leadership potential.

(Slide 54) The mentors came from a wide variety of backgrounds. They ranged in age between 20-48 years, 19 men and 12 women, all of the individuals made use of some kind of computer-based voice output system. Many of them also used speech, had light tech systems as back-ups, some also made use of gestures and signs.

(Slide 55) All of the mentors had completed at least high school, 84% had at least some college, and roughly two thirds of the individuals who participated in the mentor training were employed.

(Slide 56) The goal of the mentor leadership training component was to develop, implement, and evaluate an internet-based mentor training program and so working with the mentors, our goal was to help them develop positive and effective interpersonal communication skills, to develop collaborative problem solving skills, and to teach the mentors strategies to facilitate access to disability-related information and resources.

(Slide 57) I am not going to go through all of the training clarity in this presentation, I just wanted to introduce and quickly show you some of the strategies that we taught with respect to effective interpersonal communication skills, we taught the mentors to make use of a strategy called 'LAF,' and that's the idea that when someone presents a problem, what we try and do is listen and communicate respect by our acknowledging the importance of the problem, ask questions to try and find out more about the problems, and finally focus on what the partner was saying, so to reflect back to the part of our understanding of the problem, just to make sure that we understood the situation that they are trying to deal with.

(Slide 58) Another strategy that was taught to the mentors within the course of the leadership training program was the 'DOIT! strategy' This is a collaborative problem solving and goal setting strategy. The D step stands for 'describe the specific problem or goal.' The O step stands for 'Outline lots of ways to solve the problem or meet the goal.' I stands for 'Identify the consequences of each plan and choose the best plan.' T stands for 'Take action,' and the exclamation mark stands for 'Celebrate success when your partner meets the goal.' So again, DOIT! is a collaborative problem solving strategy. Training in the listening strategy and problem solving strategy and other additional information seeking strategy which I haven't discussed here but there is more information on that on the website that I mention in a few minutes.

(Slide 59) After they had completed the training, they were matched with 32 protégés. So younger individuals who used AAC who had requested a mentor that they could work with. There were 20 males and 12 females that participated as protégés, all those individuals had Cerebral Palsy, used augmentative and alternative communication, demonstrated functional literacy skills, and were between the ages of 13 and 31.

(Slide 60) The protégés and mentors conversed via e-mail over a period of months. During that time, the protégés identified a number of goals that they were interested in discussing with their mentor. It's interesting to look at some of these goals. They had questions around college, employment, getting involved in volunteer activities, independent living, personal care attendants, assistive technology, ways to participate more in the community and develop friendships, how to interact and communicate with unfamiliar partners, and strategies for advocating both for themselves and for other individuals.

(Slide 61) It was really exciting to see the size and the quality and the number of e-mails that were exchanged between the mentors and the protégés. Over 2800 messages were exchanged during this project. There was an average of 88 messages per mentor/protégé dyad. With some dyads there were approximately 34 messages exchanged during the year. Others we saw almost one a day going back and forth between the two participants.

(Slide 62) As I mentioned there was a wide variety of topics discussed. The variation across the topics seemed to be related to the protégé's age, interests, life circumstances, barriers encountered. The nice thing about this set-up though was that the interaction

between the mentor and the protégé was completely individualized, so it was really the interests and the needs of the protégé that drove the discussion.

(Slide 63) Some of the most frequently discussed topics included just social interaction, so just chit chat around favorite movies and sports and things that were of interest to them, community activities, education, friendships and relationships, questions about augmentative communication and interacting with the family were also very popular topics. It is kind of interesting to look at this and see that social conversation was clearly the most popular topic. To some extent it was our experience that those social conversations in a sense served to establish a foundation for the relationship, and that once trust had been built up through those social interactions, then protégés were more willing and more interested in discussing perhaps more serious topics that were of interest to them. I think it would be unrealistic to expect that simply in matching a mentor and a protégé, that the protégé is immediately going to you know open up and start to discuss issues of greatest concern to them. So we were quite pleased to see that level of social interaction taking place and we really saw that as being fundamental and important to the development of a good relationship between the mentor and the protégé.

(Slide 64) When we asked protégés and mentors about their satisfaction with the project, 96% of the protégés described themselves as very satisfied.   The things they liked best were talking to somebody that understood, sharing experiences, meeting somebody new who uses AAC, getting new ideas for doing things, sending and receiving e-mail, and being a part of something was all things that they described as important parts of the protégé project for them. Those individuals that didn't report that same high of level of satisfaction, typically their concern was that they wanted a mentor that would interact with them even more frequently. So, while some protégés for example were used to checking their e-mail two or three times a day and really wanted that level of interaction, sometimes we had mentors that maybe only checked their e-mail once or twice a week. That happened only in a very small number of cases but it is something that we would think about in future projects to try and match mentors and protégés based on how frequently they expect to interact.

(Slide 65) 92% of the protégés indicated that they would stay in touch with their mentor, and 100% of the protégés that participated said they would recommend the program to others.

(Slide 66) In speaking with the mentors about their levels of satisfaction, 97% of the mentors described themselves as very satisfied with the project. What they liked best about it was the opportunity to help someone else, getting to know someone, having an opportunity to share their experiences and also learning about the protégé's interests and concerns. The individual who did not report that same high level of satisfaction, I think was hoping to be in a more serious mentor-protégé relationship. That particular individual wasn't as interested in the social interaction that the protégé was interested in, and again I think if we were to set-up a project like this, we'd try and talk more with both mentors and protégés in the very beginning about the role, the social interactions within these relationships and our perception of the value of establishing a good social

relationship before thinking that there will be a lot of discussion of more serious topics between mentors and protégés.

(Slide 67) 90% of the mentors indicated that they would stay in touch with the protégés, and again 100% of the mentors said they would recommend the program to others.

(Slide 68) For those of you with an interest in getting more information about this project, we've been developing resource materials to support mentoring programs for individuals who use AAC. That information is available at the website that's on your screen http://mcn.ed.psu.edu/~mentor

(Slide 69) As Michael Williams has commented, *'falling in love, starting a new school, starting a new job, changing communities or homes, mastering a skill, learning a new piece of assistive technology – all are easier and more fun if the experience can be shared with and guided by someone who has "been there."* And that was really our goal of the project, to try and link up older more experienced individuals who use AAC with younger individuals who use AAC, so that those older and more experienced individuals could share some of what they had learned.

(Slide 70) And that's a picture of the website that we have developed and again the address is available two slides earlier and it provides information for those who would be interested in acting as mentors or in setting up a mentor program.

(Slide 71) We've been talking about factors associated with a high quality of life, high self-esteem, strong levels of self-determination, strong social networks and relationships. Just in the next few minutes I'd like to talk about ways that we've established strong social networks and relationships.

(Slide 72) Sometimes we think about the question, *"how do we turn new people into friends?"* and one answer to that is, *"we treat them as if they already are friends."* So you think about some of the things that you do with friends and what sort of keeps that relationship strong. One of those things is we ask our friends questions about themselves and we listen to, and respond to, their answers.

(Slide 73) So, Light, Binger, Agate & Ramsay explored the impact of training individuals who use AAC to ask partner-focused questions, what would be the impact on relationships for individuals who use AAC - ask more partner-focused questions.

(Slide 74) So some examples of partner-focused questions include things like, *"How was your weekend?" "What did you do last night?" "What's up?"* and this is popular in Pennsylvania, *"Did you watch the game?"* All questions that are meant to show an interest in the partner.

(Slide 75) The study was conducted with individuals over a range of ages. All of the individuals learned to ask partner-focused questions in real-world situations in about 80% of the opportunities. Typically this required somewhere between three and eleven hours

of instruction. The individuals who participated in the project made generalized use of partner-focused questions with new partners in new situations. Two of the five people that learned this skill on the study went on to start making up their own questions above and beyond the questions they were taught during the study, and 5 of the 6 were still using the skill 2 months after the completion of the training.

(Slide 76) It's interesting to look at the reactions of the people that were around and interacting with the individuals who used AAC. One of their teachers commented, *"it was surprising to note the reaction of the communicative partners when the individual asked a question. They showed pleasure and surprise. They seemed happy to share in the conversation."* The feedback that we got from the individuals who knew the individuals used AAC was that the individuals who used AAC were viewed as more competent, more interactive, more involved, and more interested in the partner. And these are all skills that serve to build and maintain social networks.

(Slide 77) So, again in summary, we have been talking about transition for individuals who use AAC, talking about the fact that the goals and aspirations of individuals who use AAC for their transition outcomes are going to be highly individualized. So what people are going to want to do with their lives in terms of employment and living situations and volunteer experiences and further educational activities – all of that is going to be highly individualized and related to a person's individual goals and aspirations. However, there are a number of factors that do seem to be associated with a high quality of life across individuals, both individuals with and without disabilities and those are high levels of self-esteem, strong levels of self-determination and strong social networks and relationships and what I have been trying to talk about over the past few minutes has been some activities that we can pursue to assist individuals who use AAC in enjoying the high quality of life as it relates to these issues.

(Slide 78) I would like to just close by pointing out a few additional resources that are available to assist in some of the areas that have been discussed today. ACETS, which is the augmentative communication and employment technology supports program, is operated at Temple University by the Institute on Disabilities. It is also a program under the AAC RERC. I've given contact information there on the screen; they operate a variety of services to assist individuals who use AAC in finding employment and have recently completed a manual on assisting individuals who use AAC in finding employment, so I would encourage you to contact the individuals at Temple University if you are interested in more information.

(Slide 79) The Pittsburg Employment Conference is a bi-annual conference. It's a conference with the goal of providing information and assisting individuals who use augmentative communication in finding employment. I find it a very exciting conference to attend because to the best of my knowledge it is the conference that enjoys the highest level of participation by individuals who themselves use augmentative and alternative communication. So typically in attending that conference you will find there is 100, 120, sometimes even more individuals who use augmentative communication in attendance.

So, it is just a very exciting place to be. Again, for more information there is contact information on your screen.

(Slide 80) Finally, for those of you who are interested in more information about employment projects or the Mentor Projects that we have discussed here today, I have given my contact information on the screen. The employment research was funded by the AAC RERC.

(Slide 81) In the final slides I will also provide information on some references that will provide additional information on the research that I have discussed here today.

(Slide 82) Thank you very much – I hope you have enjoyed this presentation. If you have any questions you can e-mail them to me at dbm2@psu.edu.

Thank you very much.