

The AAC-RERC Webcast Series

Duke University, Temple University,
The Pennsylvania State University,
Children's Hospital at Boston,
University of Nebraska at Lincoln,
Augmentative Communication Inc.,
State University of New York at Buffalo



Supporting Transitions to the Adult World for Individuals who use AAC



David McNaughton
The Pennsylvania State University
dbm2@psu.edu

1. Components and Outcomes

What are the key components of a successful transition?

- Employment?
- Large social network?
- Family?
- Recreational activities?

Long term outcomes for individuals who use AAC (Lund & Light, 2001)

- Outcome study to measure the impact of AAC interventions in multiple domains
 - 7 young men
 - Originally participants as preschoolers in study by Light, Collier & Parnes (1985)
 - Cerebral palsy
 - Ages 19-23 years at time of 2001 study
 - Significant speech impairments
 - Used AAC for at least 15 years
 - Used various AAC systems to communicate

Outcomes (Lund & Light, 2001)

- Educational and vocational achievement
 - 2 participants were still in high school
 - 1 was academically competitive
 - 2 participants were attending college
 - 2 participants were enrolled in a life skills program
 - 1 participant dropped out of school in 10th grade; was not employed or involved in a day program

Outcomes (Lund & Light, 2001)

- Quality of life
 - All participants reported a “positive” quality of life, but there was significant variation as to the quality reported
 - Participants differed with regards to what domains contributed to their quality of life

Contrasts in outcomes

- “Leo”
 - Unable to read at a grade 1 level
 - Dropped out of high school in 10th grade
 - Is self-determined
 - Reports a high quality of life
- “Josh”
 - Reads at a sixth grade level
 - Academically competitive in high school
 - Less satisfied with quality of life

Interpretation of Transition Outcomes

- Interpretation of outcomes depends on personal perspective
 - Goals
 - Values and priorities
 - Expectations

Factors associated with a high quality of life

- High self-esteem
- Strong levels of self-determination
- Strong social networks and relationships

2. Employment

Employment and individuals who use AAC

(Light, Stoltz, & McNaughton, 1996)

- Over 85% of individuals who use AAC are unemployed
- Employment barriers include
 - Lack of education and job preparation
 - Transportation and work-place support barriers
 - Attitudinal barriers

Who is working?

- Individuals with a range of abilities and disabilities
 - Cerebral palsy
 - Mental retardation
 - Autism



Video intro 1

- First clip
 - Larry doing a workshop presentation

Larry

- Workshop presentation

- Larry doing the workshop presentation
 - Wide variety of modes of communication
 - Voice output communication aid, sign language, translation into Spanish
- Paul
 - Young man with autism
 - Bagging groceries
 - Small portable voice output aid

Paul

- Paul
 - Young man with autism
 - Small portable voice output aid on hip

Video 2 comments

- At first store manager had been reluctant
- Paul turned out to be one of his best hires
 - Always on time
 - Concerned with job being in an orderly way

What are they doing? (McNaughton, Light, & Arnold, 2002)

- Clerical
- Laborer
- Public educator
- Educator
- Technology consultant
- Writers/artists/musicians

What does it take to make it work: Individual who uses AAC

- Marketable skills
- Effective communication skills
 - networking skills
- Strong work ethic
 - time management skills



Marketable skills

- Formal education
- Literacy
- Informal educational and work/volunteer experiences



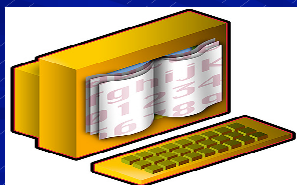
Formal education

- Graduate degree (14%)
- 2 or 4-yr college degree (18%)
- High school graduation diploma (14%)



Literacy

- Read college level texts (36%)
- Read newspapers, write letters (16%)



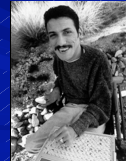
Low expectations and lack of knowledge about AAC by school professionals

- 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 (TZ)
- I didn't use all of the devices (I got before at school) because no-one taught me how to use them (KK)

Informal educational experiences

- Volunteer activities
 - Classroom aides
 - Writers
 - Presenters

- The way I got started was by volunteering at a local school. That's when someone noticed me and my abilities



Effective communication skills

- Portable voice output communication aide (76%)
- Speech or speech approximations (56%)
- Gestures or signs (36%)
- Alphabet or word boards (36%)

Have a back-up to the back-up (McNaughton, Light, & Gulla, 2003)

- 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. (Employer)

Effective communication skills (McNaughton et al., 2003)

- Not just an issue of speed or size of vocabulary
 - Positive social interaction

They (the AAC user) must start a conversation with the interviewer right from the beginning. Because, you might be the first aug com user the interviewer ever saw. By starting a conversation, you will make the interviewer comfortable and show them how intelligent you are. (KQ)

Social Networks

(Carey, Potts, Bryen, & Shankar, 2004)

- Need for
 - strong ties
 - Family, close friends
 - weak ties
 - Non-intimate colleagues
 - "Pull can be as important as push"

How did individuals secure employment?

- Family members and friends (42%)
- Professionals (33%)
- Vocational training agencies (38%)
- Government employment offices (12%)



Personal support networks

–I was taught that you need to work hard to get to where you want, yet you must be careful that you don't step on other people's toes. It is all about networking and working hard (DL)

Strong work ethic

- Time management skills
 - We don't have the luxury of being spontaneous (MC)
- Recognize positive and negative aspects of employment

Positive Aspects: Feeling Productive

- Changing public perceptions
 - I like proving everybody wrong. It does work because they learn from us. They remember, too (US)

Positive Aspects: Positive Experience

- Enjoy work, enjoy people at work
 - I enjoy working and being out in the workplace - contributing, making new friends, etc.(US)

Positive Aspects: Personal Goals

- Achieving life goals
 - Yes, I have disabilities. However it does not mean I'm 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. (NL)

Negative aspects: Impact on physical/mental health

- Adjusting to “daily grind”, dissatisfaction with job, dealing with feedback
 - Working all day is not easy, but I knew it already. I didn’t say anything about it at my job. Either I make it or I don’t. (NL)
 - It isn’t that work is difficult. It’s just boring and dry! (HD)

Negative aspects: Impact on non-employment activities

- Activities of daily living, personal life
 - 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 (HF)
 - 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 (ED)

Negative aspects: Financial issues

- Government aid
 - I’m on (government support) and can make up to \$700 a month, but you have to be careful (UZ)

Recommendations for families and educators

- Support development of employment skills
- Build communication and social skills
- Develop social network

Encourage responsibility at an early age

-
- Develop situations where individual who uses AAC needs to be involved in
 - making decisions/making plans,
 - providing directions to others,
 - following through on commitments

When skills are not enough...

- You must have a good lawyer. For my job, it took me about 2 years to get my job. Do not give up!



Develop communication skills and social competence

- Employers like positive “upbeat” people
- “After we hired (Greg) no one complained about having a cold or not being able to find a parking space”

Develop social network

- Keep “strong” ties strong
 - Keep in touch with former teachers, therapists, family members
- Develop new “weak” ties
 - Presentations at conferences
 - Join service groups
 - Electronic networking
 - ACOLUG
 - Webpages

Webpages

- 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 (ED)

- Every time you 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 augmented communicators.

- Living your life out and loud is a contribution to society.

■ M. Williams



What does it take to make it work? Workplace and society

- Knowledgeable employer
- Appropriate match between client/job
- Effective and efficient assistive technology
- Access to transportation
- Support network
 - Personal care attendant

Knowledgeable employer (McNaughton, Light, & Gulla, 2003)

- Individuals who use AAC are described as skilled, loyal, and hard working
- “He needed to be somewhere the next morning, and we had been having trouble with paratransit, which was always a problem. He slept on the floor here at the office, so he could be here on time. So, the motivation is extraordinary and I do respect that.”

Appropriate match between client and job

- 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

Effective and efficient assistive technology

- Speed
 - Workplace vocabulary
- Breakdowns
- Reluctance of co-workers to socialize
 - Multiple modes of communication

Access to transportation

- (discussing transportation) Don't take me to Baghdad first (NK)

Support network

- Personal care attendant
- Training in workplace culture
- Employer
 - Model appropriate communication skills and attitudes

Summary

- 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"
Ochocka, Roth, & Lord (1994).

Factors associated with a high quality of life

- High self-esteem
- Strong levels of self-determination
- Strong social networks and relationships

3. Mentors

Mentor
Project

The AAC Mentor Project: Sharing the Knowledge of Individuals Who Use AAC

Janice Light, David McNaughton,
Carole Krezman, & Michael Williams

Challenges for people who use AAC

- Maximize educational/vocational achievement
- Participate fully in society
- Pursue meaningful goals
- Enjoy a high quality of life

Important supports

- Encouragement from relevant role models
- Well-developed problem solving strategies
- Access to information



Williams, 1996

- 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 able-bodied professionals in the rehabilitation delivery system

Bowe, Fay and Finch (1980)

- *A mentor provides a brain to pick, a shoulder to cry on, and sometimes a kick in the pants.*
Josefowitz (1980)



AAC Mentor Project 1998-2002

- Leadership Training (over WWW)
 - To develop skills as effective mentors
 - To build leadership capacity
- Mentor Program (via E-mail)
 - To support adolescents and young adults who use AAC in solving problems and meeting personal goals

AAC Mentor Project: Leadership Training

- 31 adults
- Cerebral palsy
- Use AAC
- Demonstrate functional literacy skills
- Achieved significant goals
- Demonstrated leadership potential



Mentors

- 20-48 years old (mean = 32 years old)
- 19 men; 12 women
- AAC systems
 - computer-based voice output systems (100%)
 - light tech systems (30%)
 - speech (48%)
 - gestures & signs (30%)

Mentors continued

- Education
 - All had completed high school
 - 84% had at least some college
- Employment
 - 65% were employed

Goals of the Mentor Leadership Training

- To develop, implement & evaluate an Internet-based mentor training program
 - To develop positive and effective interpersonal communication skills
 - To develop collaborative problem solving skills
 - To teach strategies to facilitate access to disability-related information and resources

Effective Interpersonal Communication Skills

L	<u>L</u> isten and communicate respect
A	<u>A</u> sk questions
F	<u>F</u> ocus on what your partner is saying

Collaborative Problem Solving and Goal Setting Skills

D	Describe the specific problem or goal
O	Outline lots of ways to solve the problem or meet the goal
I	Identify the consequences of each plan and choose the best plan
T	Take action
!	Celebrate success when your partner meets the goal

AAC Mentor Program Participants

- 30 mentors who completed training
- 32 protégés
 - 20 males (62%) and 12 females (38%)
 - cerebral palsy
 - use AAC
 - demonstrate functional literacy skills
 - ages 13 to 31 (mean 19)

Protégé Goals

- College
- Employment / volunteer experiences
- Independent living
- Personal care attendants
- Assistive technology / computer skills
- Social participation / friendships
- Communication with unfamiliar partners
- Advocacy for self and others

AAC Mentor Program Results



- Frequency of E-mails
 - > 2, 800 messages exchanged
 - Mean of 88 messages per dyad
 - Range from 34 –363 messages per dyad in the year

AAC Mentor Program Topics

- 16 different topics discussed
- Variation across dyads as to topics discussed
 - protégé's age
 - interests
 - life circumstances
 - barriers encountered, etc.

AAC Mentor Program Topics

- Most frequently discussed topics included
 - Social conversation (mean of 39% of thought units)
 - Community activities (mean of 14%)
 - Education (mean of 7%)
 - Friendships/ relationships (mean of 6%)
 - AAC and communication (mean of 5%)
 - Family (mean of 5%)

AAC Mentor Program Satisfaction / Social validation

- 96% of protégés were very satisfied
- “Liked best”
 - Talking to someone who understood
 - Sharing experiences
 - Meeting someone new who uses AAC
 - Getting new ideas for doing things
 - Sending and receiving e-mail
 - Being “a part of something”

AAC Mentor Program Satisfaction / Social validation

- 92% of protégés indicated they would stay in touch with mentor
- 100% would recommend program to others

AAC Mentor Program Satisfaction / Social validation

- 97% of mentors were very satisfied
- “Liked best”
 - Helping someone else
 - Getting to know someone
 - Sharing similar experiences
 - Learning about the protégé’s interests and concerns

AAC Mentor Program Satisfaction / Social validation

- 90% of mentors indicated that they would stay in touch with protégés
- 100% of mentors would recommend program to others

Resource Materials

- Development of resource materials to support mentoring programs
 - Guidelines for establishing mentoring programs
 - Mentor training program
- Dissemination
 - Accessible website
<http://mcn.ed.psu.edu/~mentor>



- 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”

■ Michael Williams

AAC Mentor Project "Sharing the Knowledge of AAC Users"

[About This Site](#) • [Establishing a Mentor Project](#) • [Outcomes](#) • [Further Information](#) • [Conclusion](#)

Steps: 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

Establishing a Mentor Project

What steps are involved in starting a mentor program?

There are 10 steps involved in starting a mentor program:


1. Define the goals of the mentor program.
2. Decide how mentors and protégés will "get together" regularly.
3. Recruit qualified people to serve as mentors; provide training for these mentors.
4. Identify protégés who would benefit from the mentor program.
5. Help protégés determine their individual goals.
6. Match mentors and protégés.
7. Support mentors and protégés and trouble shoot as problems occur.
8. Evaluate the mentor program to ensure its effectiveness.
9. Revise the program as required to improve outcomes.
10. Plan for the end of the mentor program as required.

Begin with [Step 1](#).

Steps: 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

[About This Site](#) • [Establishing a Mentor Project](#) • [Outcomes](#) • [Further Information](#) • [Conclusion](#)

Copyright © 2002 The Pennsylvania State University - All rights reserved.



Factors associated with a high quality of life

- High self-esteem
- Strong levels of self-determination
- Strong social networks and relationships

4. Developing Social Networks

How do we turn new people into friends?

- We treat them as if they already are friends
- We ask them questions about themselves
- We listen to and respond to their answers

Training in partner-focused questions

Light, Binger, Agate, and Ramsay (1999)

Partner focused questions

- How was your weekend?
- What did you do last night?
- What's up?
- Did you watch the game?

Results

- All learned to ask partner-focused questions in real-world situations in 80% of opportunities
 - 3-11 hours of instruction
- Generalized use with new partners in new situations
 - 2 made up own questions
 - 5 of 6 still using skill 2 months post

Social validity

- “It was surprising to note the reaction of communicative partners when (the individual) asked a question. They showed pleasure and surprise. They seemed happy to share in the conversation”
- Viewed as more competent, more interactive, more involved, and more interested in the partner

Factors associated with a high quality of life

- High self-esteem
- Strong levels of self-determination
- Strong social networks and relationship

5. Resources

ACETS: Augmentative
Communication
and Employment
Technology Supports



The Institute on Disabilities
Pennsylvania's University Affiliated Program
at Temple University 004-00
423 Ritter Hall Annex
Philadelphia, Pa 19122
Tel. (215) 204-1356 (voice/TTY)

PEC: Pittsburgh Employment Conference

Bob Conti
SHOUT
P.O. Box 9666
Pittsburgh PA 15226
1-800-668-4202
SHOUT@SGI.NET

The AAC-RERC

- <http://www.aac-rerc.org/>
- For more information on The Employment Project, please contact David McNaughton, 227 CEDAR Building, The Pennsylvania State University, University Park, PA, 16802, dbm2@psu.edu

Resources

- AAC & Employment
■ <http://mcn.ed.psu.edu/emp/home.html>
- ACOLUG
■ <http://www.temple.edu/instituteondisabilities/acolug/>
- Email for David McNaughton - DBM2@PSU.EDU

Additional references

- Carey, A.C., Potts, B.B., Bryen, D.N., & Shankar, J. (2004). Networking towards employment: Experiences of people who use augmentative and alternative communication. *Research and Practice for Persons with Severe Disabilities*, (29), 22-34.
- Light, J.C., Binger, C., Agate, T.L., & Ramsay, K.N. (1999). Teaching partner-focused questions to individuals who use augmentative and alternative communication to enhance their communicative competence. *Journal of Speech, Language, and Hearing Research*, 42, 241-255.
- Light, J., Stoltz, B., & McNaughton, D. (1996). Community-based employment: The experiences of adults who use AAC. *Augmentative and Alternative Communication*, 12, 215-228.
- Lund, S. & Light, J. (2001). Fifteen years later: An investigation of the long-term outcomes of augmentative and alternative communication interventions. Final grant report submitted to the U.S. Department of Education Office of Special Education and Rehabilitative Services. ERIC document

- McNaughton, D., Light, J., & Arnold, K.B. (2002). "Getting your 'wheel' in the door": The successful full-time employment experiences of individuals with cerebral palsy who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 18, 59-76.
- McNaughton, D., Light, J., & Gulla, S. (2003). Opening up a "Whole new world": Employer and co-worker perspectives on working with individuals who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 19, 235-253.

Graduate Study Opportunities in Augmentative and Alternative Communication

For information on Masters and Ph.D. study opportunities in Special Education or Communication Sciences and Disorders at Penn State University, please contact David McNaughton at DBM2@PSU.EDU or 814-865-7159