Transition Strategies for Adolescents and Young Adults who use AAC

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What can the research tell us ...

- Independent living
- Employment
- Access to medical services
- Friendships and intimate relationships

Transition Goals
(McNaughton & Kennedy, 2010)

1. Have a safe place to live
2. Participate in meaningful activities
3. Maintain a reliable source of income and access to services
4. Develop friendships and intimate relationships

For Individuals who use AAC

- Access to effective, efficient and appropriate communication
  - And communication partners
- Opportunity to exercise self-determination
  - Make decisions
  - Effect change
    - (Wehmeyer, 2005)

Transition Goals
(McNaughton & Kennedy, 2010)

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Daniel Gilbert (2006)

- We try to act in ways that prepare us for the future
  - Save, diet, exercise,
- We are very bad at predicting the future
  - Age 15? Age 25?
How can we plan for the future?

- Be aware of the research
- Talk to someone who is already there
- Visit the future
- Teach skills that will allow people to adapt to new environments

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(McNaughton & Kennedy, 2010)

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Communication & Self-determination

Where people live  
(Collier & Self, 2010)

Have a Safe Place to Live

- It was the best of highs. It was the worst of terrors. I was elated. I was depressed. I smiled with joy. I cried with sorrow. I knew everything. I knew nothing. What caused these swings of emotion? Moving out on my own.
- M. Williams, 2002

Personal Care Attendants

- 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 the person who provides attendant care
- Direct care
- Give positive and constructive feedback
- Deal with conflicts and dangerous situations
- Barbara Collier, 2005
Documenting Service Routines

- Identify important contexts
- Transfers, mealtimes, toileting
- Document Service Routine
- Step-by-step description
- Binders, pages on wall, programmed into devices
- Photos
- Practice use in role-playing situations

Service Routine for Nail Care

(Collier et al., 2006)

- When cutting or cleaning my nails, it is important to know that my hand may clench. This is due to my spasticity. It does not help to ask me to relax or open my hand. I cannot control it.
- The best thing to do is
  - Gently pry open each finger
  - Hold each nail firmly when cut or clean the nail
  - Cut my nails short
  - File any jagged nails because I might scratch myself

Teach Needed Strategies

(Collier, 2007)

- Use role plays to teach needed strategies
  - Describe problem
    - I have a problem with my nails
  - State significance
    - It hurts when they have jagged edges
  - Communicate what needs to happen
    - Please follow the service routine in my book

Self-determination & Problem-Solving

(Horton, 1996)

- I tell the driver politely, at first, what needs to be done. If the driver does not heed my directions, I say, “Company rules say that is your responsibility.”
- Then if there is still no compliance, I say, “You need to call your supervisor”, followed by “All right I will call him myself”. And “Please send a supervisor” if the driver refused to tie my chair down.

For Individuals who use AAC

- Access to effective, efficient and appropriate communication
- Ability to exercise self-determination
  - Make decisions
  - Effect change
    - (Wehmeyer, 2005)
Crime and Abuse
(Bryen, Carey & Frantz, 2003)

Survey of 40 adults who use AAC

- 45% have experienced crime or abuse
- 97% knew the perpetrators
- 71% victimized multiple times
- 28% reported abuse to police

Sometimes even when we want to speak out, we don’t have the right words to do so. Most communication aids don’t come with the vocabulary necessary to end the silence about crime and abuse…we need adequate vocabulary to talk about crime and abuse, and we need to know how to use that vocabulary

Lever, 2003

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Communication and Self-determination

Encourage children and young adults to

- Communicate what they want and how they want it done
- Give polite feedback
- Problem solve
- Develop a sense of personal privacy
- Say “no” when appropriate

Visit future

Sample future living environments

- LifeLink (State College, PA)
  - High school program
  - Students plan all week for a weekend “visit” to an apartment
  - Plan menu
  - Nutrition, math, meal preparation, transportation
  - Laundry
  - Recreation
  - Community living and problem solving

Transition Goals

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Participate in Meaningful Activities

- Work
- Volunteering
- Post-Secondary Education
- Recreation and Leisure

Employment Research

<table>
<thead>
<tr>
<th>Study</th>
<th># of Participants</th>
<th>Disability</th>
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<tbody>
<tr>
<td>Isakson et al (2006)</td>
<td>1</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Light et al (1996)</td>
<td>25</td>
<td>CP, autism, TBI</td>
</tr>
<tr>
<td>McNaughton et al (2001)</td>
<td>5</td>
<td>ALS</td>
</tr>
<tr>
<td>McNaughton et al (2002)</td>
<td>8</td>
<td>CP</td>
</tr>
<tr>
<td>McNaughton et al (2006)</td>
<td>7</td>
<td>CP</td>
</tr>
<tr>
<td>McNeill et al (2008)</td>
<td>5</td>
<td>CP</td>
</tr>
<tr>
<td>Odom &amp; Upthegrove (1997)</td>
<td>1</td>
<td>CP</td>
</tr>
<tr>
<td>Storey &amp; Provost (1996)</td>
<td>2</td>
<td>DD</td>
</tr>
<tr>
<td>Wolf-Heller et al., (1996)</td>
<td>3</td>
<td>Deaf-blind</td>
</tr>
</tbody>
</table>

Employment Webcast
http://aac-rec.psu.edu/index.php/webcasts/show/id/15

Key Components of Employment

1. Developing **employee knowledge and skills** that are valued in the workplace
2. Identifying and developing jobs that are a **good match** for the skills and interests of the AAC user
3. Ensuring that needed supports are available to maintain employment success

For individuals who use AAC ...

Having a job may mean you can determine where you live, what you eat, how you spend your leisure time, how you feel about yourself, and how your neighbors and community see you as a person. In short, having a job may mean more control over what you do with your life.

(M. Williams, 1994, p. 1)

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McNaughton, Light, and Kennedy (2010)
Developing Employee Knowledge and Skills: Anthony

- I'm Anthony Arnold an augmentative and alternative communicator from Grand Forks, North Dakota. I'm a remote troubleshooter for the Prentke Romich company and I also do a lot of the beta testing on their newer communication devices such as the new ECO-2.

Communication device

- After my parents first learned about my cerebral palsy, they started taking me to therapies and a preschool program. One of the first developments was the creation of a communication board with six symbols. Communication is a very important element for employment and independent living, so you want to start laying the groundwork as early as possible, or again you will witness fewer results and the result will not be the one that you want.

In elementary school, I was fortunate to have a resource room teacher who was determined to teach me how to read come hell or high water. I must say that reading is a necessary skill to attain if you’re hoping to obtain employment some day - I can’t name a job where they don’t require basic reading skills. During elementary school, they also taught me how to spell and write, which is a skill I have to use everyday at the Prentke Romich company.

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Identifying and Developing a Good Match: “Haylie”

- Takes orders & delivers lunches once a week to clients who work in local businesses
- PRC Vantage Plus with direct selection, speech approximations, & gestures
- Reads 200 sight words, spells 10-20 words

“Haylie”

- Mother & vocational rehabilitation staff act as support persons, assisting in transportation, money management, placing orders, delivery, & recruiting clients
- Business started while in high school, has now been in operation for over 5 years

Hayley thrives on interaction with people. She likes what she does has a sense of purpose (helping others). She also likes to be “on the go”. She would be miserable idling her time away at home, or “killing time” in a segregated setting.

- McNeill et al., 2008

Micro-Enterprise (McNeill, McNaughton, Light, 2008)

- A form of self-employment, requiring the support of others for success.
- The interests and talents of the individual with a disability drive the vision of the business.
- Priorities include participation in the community, interaction with others, and gaining a sense of contribution and self-worth.
- Making a profit is not always a priority

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**Ben**

- 28
- Organic Egg Farmer
- Uses a Dynavox 4 with single switch and audio scanning system
- Participated in high school education
- Support persons
  - family,
  - friends in the organic community,
  - vocational rehabilitation staff

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**Key Components of Employment**

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**Benefits of Volunteer Activities**

- Financial support
- Opportunity to interact socially
- Enhanced self-esteem
- Contributing to society

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**Volunteering: Rebecca**

- Is a member of a dance troupe that has performed internationally
- Volunteers as a “listener” in an elementary school classroom
- Helps as a guide at a local museum

http://www.rebeccabeayni.com/

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**Post-Secondary Education**

- Organization
- Scheduling
- Support from family

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**Post-Secondary Education**

*College Life and AAC: Just Do It*

Beth Anne Luciani
Sam Horochak
David McNaughton
Recreation and Leisure

(Dattilo, Benedek-Wood, & McLeod, 2010)

- Experience enjoyment
- Build friendships
- Improve self-confidence
- Engage in self-expression

Transition Goals

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Medical Services

(Bailardini & Waller, 2010)

<table>
<thead>
<tr>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Parents coordinate care</td>
<td>• Individuals are responsible for managing their own health care, including identifying service providers and advocating for needed services</td>
</tr>
<tr>
<td>• Children's rehabilitation facilities often provide “one-stop” coordinated services</td>
<td>• Individuals may need to interact with and coordinate information between - general practitioners, - medical specialists and - habilitation / rehabilitation specialists</td>
</tr>
<tr>
<td>• Government guarantees of health and rehabilitation services</td>
<td>• Individuals need to be able to advocate for adult services</td>
</tr>
</tbody>
</table>

What do doctors expect?

(Marvel et al., 1999)

- Typical medical appointment: ___ minutes
- Time for patient to talk before being interrupted: ___ seconds

Needed skills

(Bailardini & Waller, 2010)

1. Introduce yourself and your communication system;
2. Use appropriate vocabulary and language to communicate concerns and needs;
3. Use appropriate communication strategies to ensure that previous health care and current health concerns are understood by the health professional.

Communication Passport

http://www.accpc.ca/pdfs/passport.pdf
Health Passport

- [http://www.healthpassport.co.uk/index.asp](http://www.healthpassport.co.uk/index.asp)
- Name
- Address
- Emergency and case manager contact information
- Insurance information
- Primary physician
- Current medical info and medications, allergies, diet restrictions,

Vocabulary

- [http://disabilities.temple.edu/aacvocabulary/e4all.shtml](http://disabilities.temple.edu/aacvocabulary/e4all.shtml)

Needed skills

- Children
  - How AAC equipment should be set up and why it is important
  - Ask for AAC device
  - Make sure it is charged
- Adolescents
  - Be familiar with names of medication, schedule
  - Take leadership role in medical appointments and meetings

Communication

[http://www.patientprovidercommunication.org/](http://www.patientprovidercommunication.org/)

Connecting to Communities

[http://www.accpc.ca/connectingtocommunities.htm](http://www.accpc.ca/connectingtocommunities.htm)

Communication & Self-determination
Individuals with chronic disabilities face unique threats & challenges; and they need robust social networks to support them so they can remain resilient and experience a high quality of life.”

(David Beukelman, ACN, 2003)
Circle of Friends: Social Map

- In the center is the child and their family.
- Circle 2: Child's friends.
- Circle 3: Acquaintances (classmates).
- Circle 4: Paid Workers
- Circle 5: Unfamiliar partners

The Mentor Project
Sharing the Knowledge of AAC Users

Janice Light, David McNaughton, Carole Krezman, Michael Williams
Maija Gulens, Jessica Currall, Alix Galskoy, Marleah Herman, & Kevin Cohen

Mentor Project: Leadership Training

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

Important supports

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

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)
Communication skills
(McNaughton & Vostal, 2010)

DOIT!
(Light et al, 2007)

AAC Mentor Program

- Correspond with mentors via E-mail on a regular basis
- Social interaction & support
- Problem solving
- Goal setting
- Interaction for a period of one year

AAC Mentor Program

- Mentors and protégés matched
- Regular interactions between the dyads
- Frequency of E-mails
  - Mean 3-4 messages per week
  - Range 1 to 12 per week

AAC Mentor Program

- Social conversation
- College – accessibility issues
- Friendships
- Loneliness
- Talking to unfamiliar partners
- Coping with disability

Barriers to Relationships: Protege

- I cannot get any friends.
- The other kids at school are rude. ... I mean I don’t have any friends in school. They just freak out about my chair. ... I’m too tired with everyone’s reactions. ... I gave up with my peers.
Barriers to Relationships: Mentor

- Why are people scared of people in wheelchairs? GOOD QUESTION Pal. I have always thought it was because those other people just don’t understand that we (disabled people with CP and other alike disabilities) are as smart, caring, funny, and loving as THEY are underneath these bodies of ours which don’t walk, talk, or work for US as well as their bodies do, you know?

Barriers to Relationships: Mentor

- To me the people who are scared of folks in wheelchairs are just DUMB about what [we] (disabled folks) can do, you know? At least that’s what I have thought always about that! I know what you’re going through. When I was in high school I was called names and made fun of. And all I had was a letter board to communicate with.

Strategies to promote friendships: Mentor

- So you think you don’t have any friends in school... Do you ask other students questions about themselves, about the homework assignments, and school activities?? Sometimes you need to focus on them first before they will focus on you.

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

- 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

Summary
Daniel Gilbert

- When looking back on their past, people are more likely to regret things they did not try, then to regret things they did try and that did not turn out as hoped.

Brookes text

- Michael Wehmeyer, Beth Foley, Erik Carter, Christy Horn, Dave Hingsburger, Barbara Collier, Sue Balandin, Laura Ball
- Pamela Kennedy, Tracy Rackensperger, John Draper, Anthony Arnold, Lateef McLeod.

Pittsburgh Employment Conference
http://www.shoutaac.org/welcome.htm

Div 12 Conference

11th Annual Conference Augmentive and Alternative Communication (AAC)

PROFESSIONAL PREPARATION FOR SPEECH-LANGUAGE PATHOLOGISTS AS AAC PRACTITIONERS

WHEN:

WHERE:
Caribe Royale All-Suite Hotel and Convention Center, Orlando, Florida

TOPICS:
Effective approaches to pre-service and in-service professional preparation for speech-language pathologists

For more information on lodging and registration:
http://www.asha.org/convention/div_12.htm

http://mcn.edu.psu.edu/dbm/2010/ASHA.html

ASHA 2010,

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A Safe Place to Live
Michael Williams webinar

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