



**Communication,  
Self-Determination,  
and Community:  
AAC Strategies to  
Support Transition**

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**Transition Goals**  
(McNaughton & Kennedy, 2010)

1. Have a safe and supportive place to live
2. Participate in meaningful activities
3. Maintain access to needed services
4. Develop friendships and intimate relationships

**Communication and Self-determination**

- Making and acting upon decisions in your life
  - Big issues
    - *Where to live*
  - Small issues
    - *What to eat for breakfast*

**Average American**

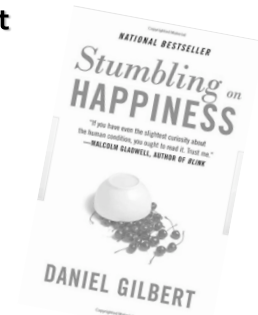
- Moves more than 6 times
- Changes jobs more than 10 times
- Students change their college major an average of 3 times

## People who require AAC

- Will interact with a wide variety of people
  - Need to be familiar with their communication system
  - Need to be familiar with their needs and goals

## 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?



## Plan for the future

- *The future is already here, it is just unevenly distributed*
  - Be aware of the research
  - Visit the future
  - Talk to someone who is already there


## Transition Goals

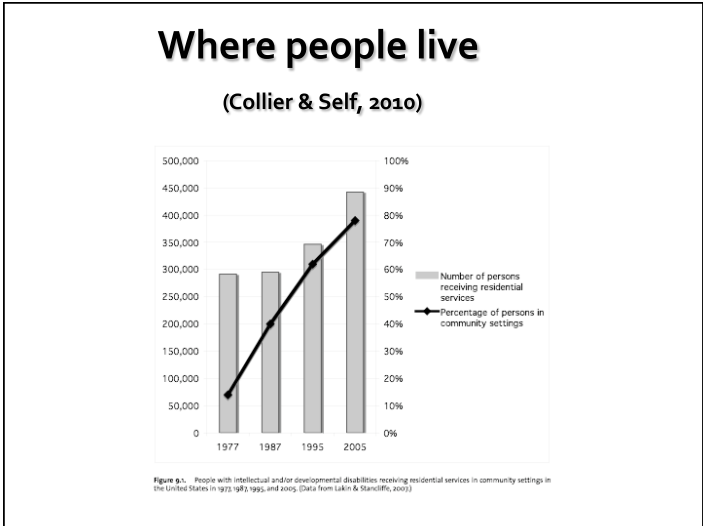
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## Have a Safe and Supportive Place to Live

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- 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, 2001 



## Personal Care Attendants


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- 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

## Directing Care

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- The three things you need to have a good relationship with your workers are communication, communication, and communication
  - Feucht, 2001



## Documenting Service Routines

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- 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)


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- 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



I spent a year writing up my service plans for different situations. I Put them in a binder. I have instructions on how I want people to talk to me; how I can communicate with them; what I want done every morning; how to assist me when I am eating; how to lift me out of my wheelchair; etc.

This is one of the best things I have ever done. It has made a major difference when I went to camp where people didn't know me. I wish I had done it when I was younger.



- I had a lot of problems when I first started working with attendants. The biggest problem was communication. I just didn't know how to get my point across without getting mad.

## 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 (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.

## Having a Safe Place to Live


- 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


## 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





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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

## My Student: What do they need to learn?



- Student:
- Goal:
- Teaching Opportunity:

● *Introducing communication system, documenting and teaching service routines to others, giving feedback to staff, reporting inappropriate behavior by staff,*

## My Student

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- Student: Michael
- Goal: Giving praise and constructive feedback to classroom aides about how he is fed
- Teaching Opportunity:
  - Discussion,
  - role-play developing positive rules
    - describe goal
    - Outline alternatives ...

## Transition Goals

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

## Participate in Meaningful Activities

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

## For individuals who use AAC ...

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*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)

## Employment Research

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

## Importance of Employment



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

## Barriers to Employment




- Attitudinal barriers
- Inadequate educational preparation
- Lack of appropriate community supports
  - Transportation
  - Supports for Activities-of-Daily-Living

## 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



**Key Components of Employment** 



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1. **Developing employee knowledge and skills that are valued in the workplace**
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3. **Ensuring that needed supports are available to maintain employment success**

**Developing Employee Knowledge and Skills: Anthony** 


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- **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 device such as the new ECO-2.**






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**Working for companies such as the Prentke Romich company is a great goal to have in mind, but it did take years of preparation to get to this point. I'd like to believe my transition to adulthood, independent living, and employment started to happen on the day my parents learned of my diagnosis of cerebral palsy, because the longer you put off the educational and rehabilitation, the less likely it is that you will achieve the goals you want.**




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- **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 good they also taught me how to spell and write, which is a skill I have to use everyday at the Prentke Romich company.

## Communication device



- I was fortunate to have had a communication device in second grade, and I must say it really allowed my teachers and my parents to not only educate me but to prepare me for independent living and employment someday. When I first received my *Touch Talker*, I remember that was the happiest day of my childhood. I finally had a way of communicating without having somebody always there reading my board.

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**Identifying and Developing  
a Good Match: "Haylie"** 

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- 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: Hello
- Secretary: Hello
- Haylie: I helped at the food pantry at church on Monday
- Secretary: Nice!
- Haylie: Would you like to order lunch from Heppelman's House of Pizza?
- Secretary: No thank you, I'm all set today.
- Haylie: What are you having for lunch today?
- Secretary: Leftovers from home!
- Haylie: Have a nice day!
- Vocational Rehab Support: OK, let's go ask someone else .
- Secretary: Bye, thanks.

**"Haylie"** 

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- 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



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- *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

- 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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## Bob

- 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

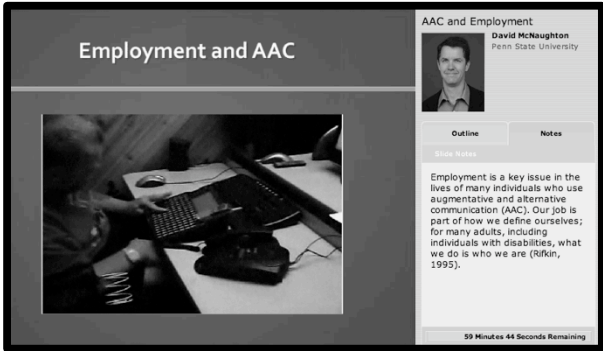
**Key Components of Employment** 


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**Employment Webcast**   
<http://aac-rerc.psu.edu/index.php/webcasts/show/id/15>

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**For individuals who use AAC ...** 

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*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)

**Benefits of Volunteer Activities** 

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

## 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/>



## Post-Secondary Education



### College Life and AAC: Just Do It



Beth Anne Luciani  
Sam Horochak  
David McNaughton



## Post-Secondary Education



- Organization
- Scheduling
- Support from family

## Recreation and Leisure



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

## "Ben" and literacy

- 13 years old
- Seizure disorder
- Visual impairment
- Attending a special school for students with autism
  - Participating in life skills class
- Communicates telegraphically using
  - Sign approximations /gestures
  - Facial expressions
  - Speech Generating Device

## Building Reading and Writing Skills

- Start with student's interests
  - Build motivation /interest
- Build positive rapport
  - Ensure success /provide positive feedback
- Apply skills in the context of meaningful reading activities early on
  - Utilize highly motivating reading materials
  - Focus on personal experiences
    - Enhance motivation
    - Provide context to support understanding

## Instruction in sight word recognition

- Incorporate instruction in sight word recognition early on
- Introduce highly motivating words
- Build success reading motivating texts


## Ben - Results

- Results after approximately 55 hours of instruction (16 months)
  - 9 years old
- Letter sound correspondences
  - Increased rate of acquisition
  - Knows 19 letter-sound correspondences
    - a, m, t, b, i, r, o, c, e, g, u, l, n, s, d, h, f, p, and j

>90% accuracy from keyboard

### Ben - Results

- Single word reading/ decoding
  - Reads 60+ words
  - >90% accuracy
- Reading with wide range of books
  - Reads short sentences / simple stories independently
  - >90% accuracy
  - Reads successfully with adults and peers

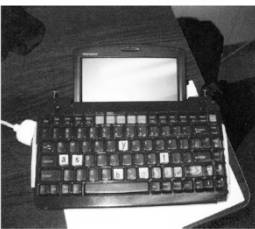
### Ben - Results

- Early writing
  - Locates letters on keyboard
  - Types known cvc words accurately
  - Learning to type simple sentences
- Continued increases in language skills
  - Use of written language to build language skills
    - Expanding vocabulary
    - Building syntax

### Literacy Instruction

- Independently finds preferred videos on YouTube
- Spells short stories on preferred topics
  - *lo mom*
- Texting and emailing are very realistic goals

### Shared reading Personalized book about Penn State

cookie	rudolph	
spoon	computer	

Bren reads words.
Bren types words.




## Literacy

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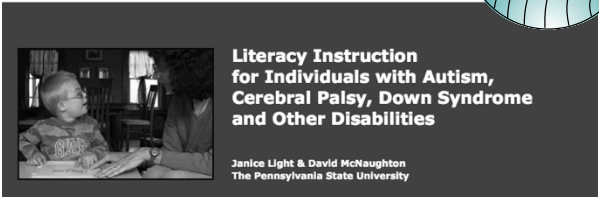
- Communication
- Self-Determination
  - Making choices and decisions

- What others think of him?
- What he thinks of himself?



## AACliteracy.psu.edu

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**Home page**

- What is the purpose of this website
- Meet one of our students

**Student success stories**

**FAQ about the curriculum**

**What is the purpose of this website?**


This website provides guidelines for teaching literacy skills to learners with special needs, especially learners with complex communication needs

- Autism spectrum disorders
- Cerebral palsy
- Down syndrome
- Developmental apraxia
- Multiple disabilities.

## Transition Goals

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1. Have a safe place to live
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### Medical Services (McNaughton et al, 2011)

Children	Adults
Parents coordinate care	Individuals are responsible for managing their own health care, including identifying service providers and advocating for needed services
Children’s rehabilitation facilities often provide “one-stop” coordinated services	Individuals may need to interact with and coordinate information between <ul style="list-style-type: none"> <li>• general practitioners,</li> <li>• medical specialists and</li> <li>• habilitation / rehabilitation specialists</li> </ul>
Government guarantees of health and rehabilitation services	Individuals need to be able to advocate for adult services

## What do doctors expect?

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- Typical medical appointment : \_\_\_ minutes
- Time for patient to talk before being interrupted?
  - \_\_\_ seconds

## Needed skills

(Ballandin & Waller, 2010)

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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>

**HOW I COMMUNICATE**

My name is:

I have difficulty speaking but I can hear and understand what you say.

This is how I communicate:

Yes:

No:

I want to communicate something:

How I use my communication display:


How I use my device:

**THINGS TO KNOW WHEN COMMUNICATING WITH ME**

- Talk to me like an adult
- Speak directly to me, not to the person who may be accompanying me
- Do not speak loudly, slowly or in a condescending manner
- Ask me if I want someone to help me communicate my messages to you - see list of facilitators
- Give me time to communicate

**REMEMBER**

- I can make my own decisions
- I need you to respect my privacy at all times. Please do not discuss issues regarding me with other people unless I give you permission.
- I need you to keep me informed of everything that is going on.




## Health Passport


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- <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,

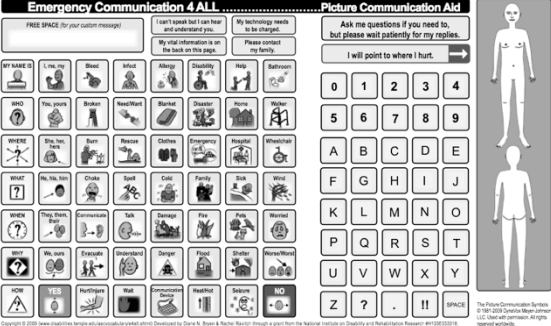





# Vocabulary



● <http://disabilities.temple.edu/aacvocabulary/e4all.shtml>



The interface shows two communication aids. The left one is 'Emergency Communication 4 ALL' with sections for 'FREE SPACE for your custom message!', 'I can't speak but I can read and understand you.', and 'My vital information is on the back of this page.' The right one is 'Picture Communication Aid' with a grid of icons for body parts and a keyboard. A human figure is shown on the right for pointing to injuries.



## 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

## <http://www.accpc.ca/connectingtocommunities.htm>



The banner shows two people looking at a document together. The text 'Connecting to Communities' is overlaid on the image.






## My Student


- Student:
- Goal:
- Teaching Opportunity:

- *make a medical appointment, provide a medical history, describe symptoms in an efficient manner, ask questions if they don't understand*

<http://www.patientprovidercommunication.org/> 

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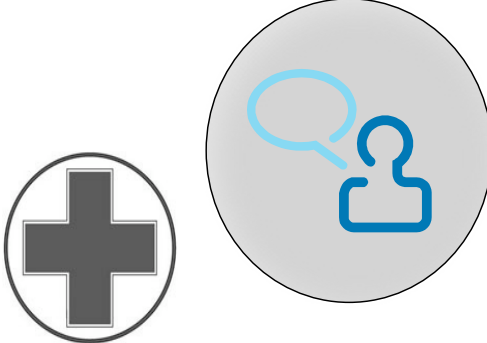
*Communication*



*Is The Joint Establishment Of Meaning*

**Communication & Self-determination**


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**Transition Goals**

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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
  - Social networks (Blackstone)
    - Circle of Friends
    - Mentor Project
  - Support Networks
  - Intimate Relationships
  - Informed consent



**Friendships and Intimate Relationships** 

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- Meaningful activities lead to friendship opportunities
- Friendships lead to opportunities for meaningful activities

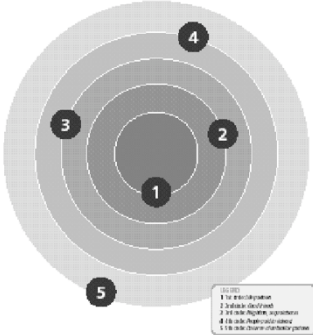



## Who is in your circles?

Blackstone & Hunt-Berg, Adapted from Marsha Forest, Judith Snow, et. al.

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1. Family
2. Friends
3. Acquaintances
4. Paid workers
5. Unfamiliar partners





“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)



## *Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners*

**Sarah Blackstone and Mary Hunt Berg, Augmentative Communication News**




## Social Networking/Circle of Friends

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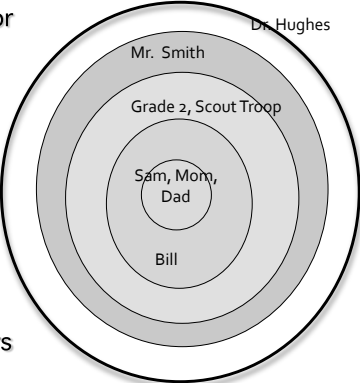
- Circle of Friends is a program for children who have difficulties making friendships. The object is to make sure the child is included in activities and feel a part of a group. A facilitator is required and could be a parent, counselor, or teacher.



### Circle of Friends: Social Map

A social "map" is prepared for the child with the child's help.

- 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



### Circle of Friends: Next Steps

- A meeting is held for the entire class.
- The system is explained to the class by 1 or 2 classmates who have volunteered to be mapped.
  - Their maps are drawn (usually lots of friends)
- Then the map is drawn for the child with disabilities.
  - Volunteers are asked to be in the child's circles
  - These children act as mentors for the child.

### Circle of Friends - Role of Mentors

- These classmates make sure they greet the child, walk to class with him or be friendly or helpful in other ways.
- There are weekly meetings (usually 15-20 minutes) in which the mentors talk about what the good things were that happened that week and then they discuss behaviors which may have caused problems and suggest ways to correct them.

### 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

Miniseminar presented at the ISAAC conference  
Washington DC, August 2000

## Challenges



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

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## Important supports



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

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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

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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)

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## Mentor Project: Leadership Training



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



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## Communication skills




## 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

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## 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

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## AAC Mentor Program Topics



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

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## 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?




- 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"

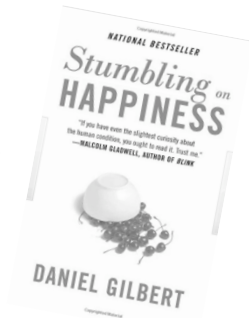
AAC Mentor Program  
Satisfaction / Social validation



- 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

## Daniel Gilbert

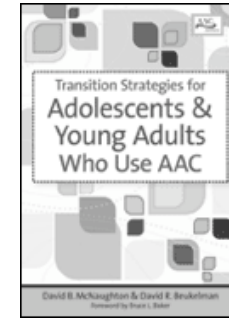
- When looking back on their past, people are more likely to regret things they **did not try**, then to regret things they **did try** and that did not turn out as hoped



## 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,



<http://mcn.educ.psu.edu/dbm/2011/philadelphia.html>

**Lecture Series on Disability**  
at Temple University



<p>A safe place to live Meaningful activities Access to medical services Friends and relationships</p>	<p><b>Communication, Self-Determination, and Community: AAC Strategies to Support Transition</b> (McNaughton, D.)</p> <p>Updated Handout ("complete" set of slides)</p>
<p><b>A Safe Place to Live</b> Michael Williams (webcast)</p>	<p><b>Meaningful Activities</b> Employment (webcast) (webcast) Racheca Beazley (webcast) Beth Anne Lusk's webcast (College life) Anne Abbott (artist) Liberty and AAC (webcast)</p>

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