

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

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Looking forward













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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


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Communication & Self-determination





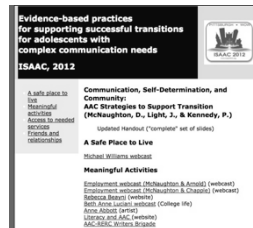






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aac-rerc.psu.edu > ISAAC

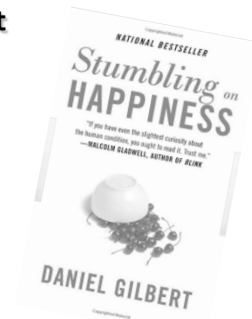


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Daniel Gilbert (2006)

- 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?



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Average American

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

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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

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Transition Goals

1. Have a safe and supportive place to live
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Have a Safe and Supportive 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, 2001



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Where people live

(Collier & Self, 2010)

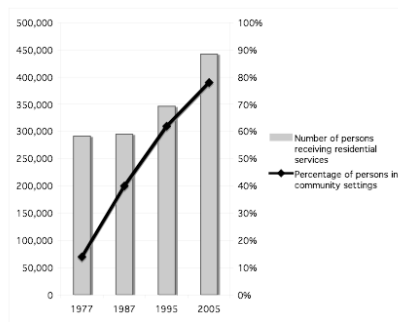


Figure 9-1. People with intellectual and/or developmental disabilities receiving residential services in community settings in the United States in 1977, 1987, 1995, and 2005. (Data from Lakin & Standiford, 2007)

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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

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Directing Care



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



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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

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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

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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.

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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*

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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.

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Having a Safe Place to Live

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

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Communication & Self-determination



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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

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- 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
- Develop a network of trusted adults (beyond their family)

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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



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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,*

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My Student



- Student: Michael
- Goal: Giving praise and constructive feedback to classroom aides about how he is fed
- Teaching Opportunity:
 - Discussion,
 - Role-play developing positive rules
 - Practice with student teachers

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Transition Goals


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



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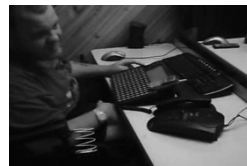
Participate in Meaningful Activities

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



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Benefits of Employment



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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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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

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Importance of Employment



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

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Barriers to Employment



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

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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

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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 device such as the new ECO-2.

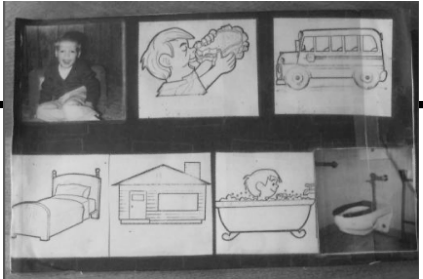


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Working for companies such as the Pretke Romich company is a great goal to have in mind, but it did take years of preparation to get to this point. I'd like to believe my transition to adulthood, independent living, and employment started to happen 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 Pretke Romich company.

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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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Key Components of Employment



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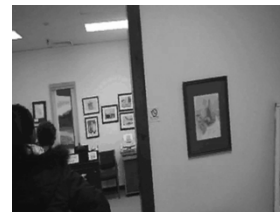
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Identifying and Developing a Good Match: "Haylie"



- 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

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- 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"



- 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



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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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Key Components of Employment



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Key Components of Employment



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Key Components of Employment




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3. Ensuring that needed supports are available to maintain employment success

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Employment Webcast (with Anthony Arnold)



Employment and AAC



AAC and Employment
David McNaughton
Penn State University

Outline

- 1) Demonstration...
- 1) Chapple vid...
- 1) Vocational Co...
- 1.1) Areas of E...
- 1.1) Areas of E...
- 1.1) Areas of E...
- 1.2) Vocabulary
- 1.3) Communi...
- 1.3) Communi...
- 2) Demonstrat...

Notes

Employment is a key issue in the lives of many individuals who use augmentative and alternative communication (AAC). Our job is part of how we define ourselves; for many adults, including individuals with disabilities, what we do is who we are (Rifkin, 1995).

59 Minutes 44 Seconds Remaining

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Employment Webcast (with David Chapple)





Slide Title	Duration	Status
AAC and Com...	00:12	✓
David McNaug...	00:37	✓
David Chapple	03:19	✓
Communicatio...	02:13	✓
Learning Objec...	01:01	✓
Planning for th...	00:41	✓
1) Demonstrat...	00:50	✓
1) Chapple vid...	02:06	✓
Vocational Co...	01:50	✓
1.1) Areas of E...	01:18	✓
1.1) Areas of E...	01:05	✓
1.1) Areas of E...	02:27	✓
1.2) Vocabulary	03:30	✓
1.3) Communi...	02:49	✓
1.3) Communi...	02:29	✓
2) Demonstrat...	00:31	✓

1.1) Areas of Expertise: Preparation

Preparation and "On the Job" Training

- David Chapple
 - College degree in computer programming
 - Life experience in using AAC
- Anthony Arnold
 - Life long ambition to work for an AT manufacturer
 - Summer job at computer repair shop

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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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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/>



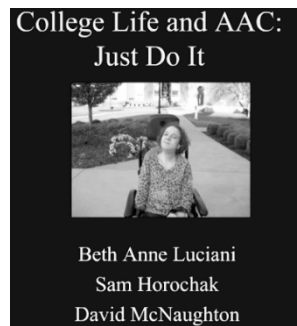
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Beayni video



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Post-Secondary Education



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Post-Secondary Education

- Organization
- Scheduling
- Support from family



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Recreation and Leisure

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

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Recreation and Leisure



● Anne Abbot



"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

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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

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Instruction in sight word recognition



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

youtube	rainbow
sing	high five

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Literacy Instruction



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

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Shared reading Personalized book about Penn State



Bren reads words.

Bren types words.

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Shared reading Personalized book about Penn State



Bren reads a book.

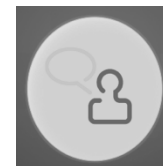


Janice says, wow.

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Literacy

- Communication
- Self-Determination
 - Making choices and decisions
- What others think of him?
- What he thinks of himself?



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AACliteracy.psu.edu



**Literacy Instruction
for Individuals with Autism,
Cerebral Palsy, Down Syndrome
and Other Disabilities**

Janice Light & David McNaughton
The Pennsylvania State University

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

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"> • general practitioners, • medical specialists and • habilitation / rehabilitation specialists
Government guarantees of health and rehabilitation services	Individuals need to be able to advocate for adult services

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What do doctors expect?

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

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Needed skills

(Ballandin & 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.

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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.

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Health Passport



- <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,



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Vocabulary



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

Emergency Communication 4 ALL										Picture Communication Aid									
FREE SPACE (for your custom message)										Ask me questions if you need to, but please wait patiently for my replies.									
I can't speak but I can hear and understand you.										I will point to where I hurt.									
My information is on the back of this page.										I will point to where I hurt.									
Please contact my family.										I will point to where I hurt.									
MY NAME IS	NAME	AGE	SEX	HAIR	HEIGHT	WEIGHT	DISABILITY	EMERGENCY	ALLERGENS	0	1	2	3	4					
IND	IND	IND	IND	IND	IND	IND	IND	IND	IND	5	6	7	8	9					
WHERE	WHERE	WHERE	WHERE	WHERE	WHERE	WHERE	WHERE	WHERE	WHERE	A	B	C	D	E					
WHAT	WHAT	WHAT	WHAT	WHAT	WHAT	WHAT	WHAT	WHAT	WHAT	F	G	H	I	J					
WHEN	WHEN	WHEN	WHEN	WHEN	WHEN	WHEN	WHEN	WHEN	WHEN	K	L	M	N	O					
HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	P	Q	R	S	T					
WHY	WHY	WHY	WHY	WHY	WHY	WHY	WHY	WHY	WHY	U	V	W	X	Y					
HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	HOW	Z	?	!!	EMERGENCY						

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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

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Communication Access to Goods and Services



Communicating Matters

many people have difficulty understanding their speech and / or their ability to understand what someone else is saying.

People with communication disabilities have a right to equal access to your goods and services.

This means, you should know

- How to show respect to people who have communication disabilities
- How to understand what people are



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Leadership role in meetings

Chapter 5 Having Your Say at a Meeting

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Communication & Self-determination



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Transition Goals

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
 - Support Networks
 - Intimate Relationships
 - Informed consent



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Friendships and Intimate Relationships



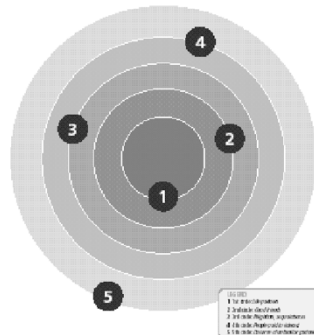
- Meaningful activities lead to friendship opportunities
- Friendships lead to opportunities for meaningful activities



Who is in your circles?

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

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

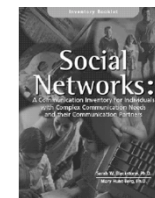
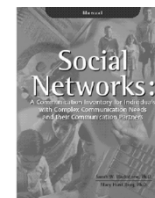


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Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners



Sarah Blackstone and Mary Hunt Berg,
Augmentative Communication News



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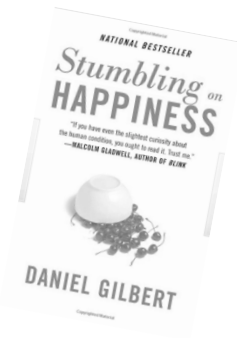


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Daniel Gilbert

- 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



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Learn from the future

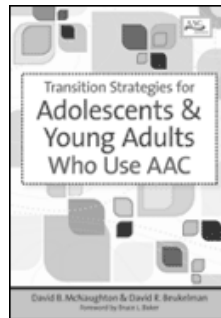


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Brookes text

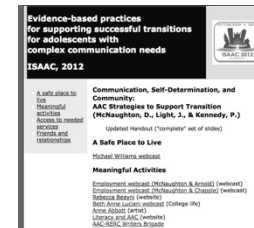


- Michael Wehmeyer, Beth Foley, Erik Carter, Christy Horn, Dave Hingsburger, Barbara Collier, Sue Balandin, Laura Ball
- Pamela Kennedy, Tracy Rackensperger, John Draper, Anthony Arnold, Lateef McLeod,



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http://mcn.educ.psu.edu/dbm/2012/ISAAC_transition_2012.html



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