

## Communication Access for All: Changing Practices, Policies, and Technologies

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Monterey, CA

**AAC FOR EVERYONE**

University of Göteborg, Sweden

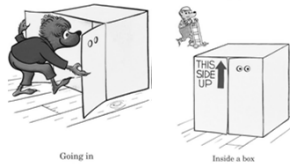
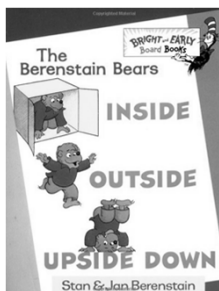
June 2, 2014

## From Monterey to Göteborg



Thank YOU!

## Inside, Outside and Upside Down



The Who? What?  
Where? When? Why  
and How?  
of AAC/AT are changing

Do people who use AAC have  
limited communication  
access?  
Where, when, how, why?

Talk with person seated next to you

## Preview

### New opportunities for AAC and AT stakeholders

- Broader use of AAC/AT tools, technologies, strategies.
- Using AAC knowledge and skills to overcome communication barriers for more people.
- Address **RIGHT to communicate** in healthcare, justice, education, community businesses & services, local government.

**What can you do? What should do?  
How might you make a difference?**

## The Times They Are a'Changing



## CHANGES Technology, Policy, Practice

- We live in a global society
- Mainstream information and communication technologies are ubiquitous and mobile
- The nature of "communication" has changed
- Communication Access is increasingly recognized as a "human/civil rights" issue




## Current Threats to AAC

- AAC industry**
- Service delivery**
- Maintenance and repair issues**
- Information overload**
- Resources that support integration/usability of multiple devices**


UNCERTAINTY

**CRISIS**  
危機  
A time of danger;

**Role of our professional organizations**

**Not even at the table**

A time of opportunity;





## Communication Access and AAC "Crisis"



DANGER
OPPORTUNITY

## Paradigm Shift?

**Figure 2**  
Paradigm shift – a change of perspective on the subject


You see a picture but what are you looking at?

### Augmentative and Alternative Communication (AAC)

Communication Access

### for All (CAA)

"Sometimes you need to look at Life from a different perspective."



What other groups face communication barriers?  
How might they benefit from "AAC"?

• Augmentative and alternative communication refers to the use of

- strategies
- techniques
- low-tech tools
- high-tech devices
- access options

???

**CAA**

1. People with complex communication needs should have same access rights as others. THEY DON'T.

2. Other groups can benefit. AAC stakeholders have knowledge & skills to share. NOT HAPPENING.

3. AAC/AT only benefits people with CCN. THAT IS NOT TRUE. LIMITS POTENTIAL IMPACT.

4. What if we don't shift our paradigm? THREAT TO SERVICE DELIVERY, AAC INDUSTRY, CONSUMER SUPPORTS, ACCESS TO TECHNOLOGIES.

5. Mainstream technology. A GAME CHANGER.

So Dad, how do you like the iPad we bought you?



**AAC industry**

**Service delivery**

**Maintenance and repair issues**

**Information overload**

**Resources that support integration/usability of multiple devices**

UNCERTAINTY

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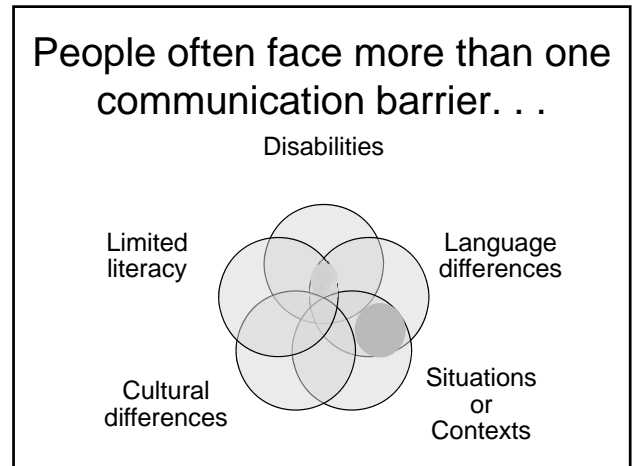
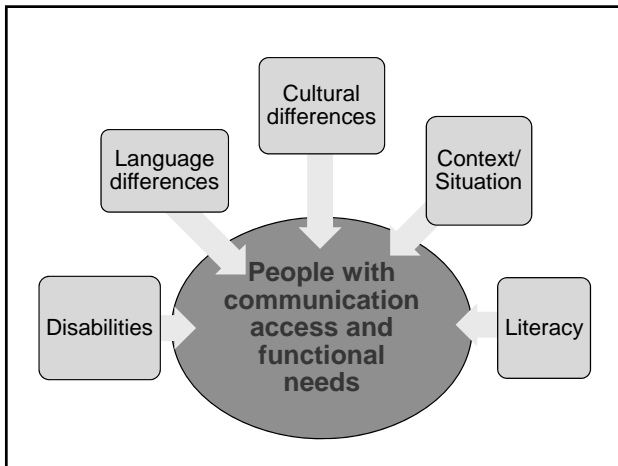
A Seat at the Table

Not even at the table



Opportunities:  
Kommunikations curbcuts





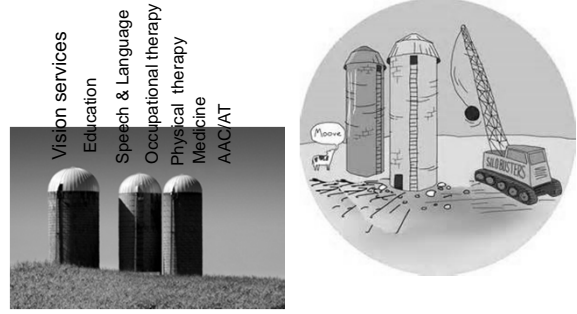
- ### What do AAC stakeholders have to offer?
- Experience supporting participation
  - Understanding of language & language disorders
  - Broad understanding of communication
  - Skill in addressing physical and cognitive access issues
  - Know how in use of technology as a communication tool
  - Get beyond "Gee Whiz Bang" factor of new technologies
  - Creativity in solving complex communication problems
  - Expanding research base - demonstrate effectiveness of AAC approaches
  - We "work well with others"
  - Long history of advocacy
  - People who are "retiring"
  - Advocates who work outside day-to-day AAC
  - etc. ....

- ## 3 ACTIONS
1. Shift our perspective
  2. Break down professional silos
  3. Be at the table.
    - Participate in discussions about communication access to: Healthcare, justice, businesses and services, government, education, etc.

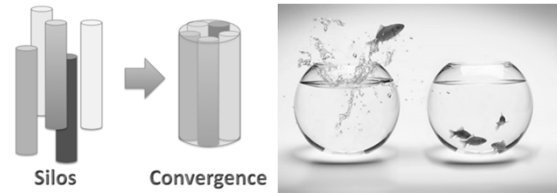
### 1. Need to shift perspectives



### 2. Need to Break Down Professional Silos



### 3. Need to be AT the table



Who has a seat? Local, regional, national, international levels?



### Law & Public Policy



## “Relevant Rules and Documents” Sweden

- A strategy for the implementation of disability policy, 2011-2016, memorandum
- Discrimination Act (2008:567)
- Social Services Act (2001:453)
- Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387)
- Assistance Compensation Act (1993:389)

## “Improving access to different domains of the environment, including

- Buildings and roads
- Transportation
- Information
- Communication



*These domains are interconnected – people with disabilities will not be able to benefit fully from improvements in one domain if the others remain inaccessible.”*

(World Report on Disability, 2011, p.169).



- *“Individuals with communication disabilities such as hearing impairment or speech impairment are at a significant social disadvantage, in both developing and developed countries ... particularly in sectors where effective communication is critical – such as those of healthcare, education, local government and justice”*

(World Report on Disability, 2011, pg. 170, 172).



## Changing Demographics

More people will experience communication challenges

- Increase in life expectancy
- Medical advances → disabilities
- Mobility of societies: multi-linguistic/multicultural differences.
- Proliferation of information and communication technologies

## Changing Technologies

- Mainstream technologies support learning/information & communication access
- Acceptance across age span
- New methods emerging
- Preferences changing



## Changing Expectations



## Changing Expectations



## AAC technologies of the future need to

- Provide relevant and desired, "just in time" communication supports for all who need it
- Be easy to learn and to use
- Enable people to
  - Be bilingual
  - Use multiple devices
  - Use multiple access methods
  - Access mainstream technologies
- Provide access to full participation (education, employment, healthcare, community, recreation, relationships, social networking. . .)



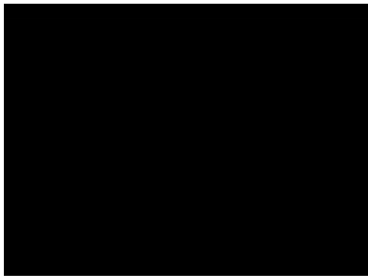
<http://aac-rerc.com>

## Not all Powerful Communication Technologies are electronic OR come in boxes Hands Free Wheeled Mobility



The Bridge School  
Christine Wright Ott

## Te Amo Mama!



**COMMUNICATION ACCESS FOR ALL  
FROM AAC TO CAA**





# COMMUNICATION ACCESS FOR ALL FROM AAC TO CAA

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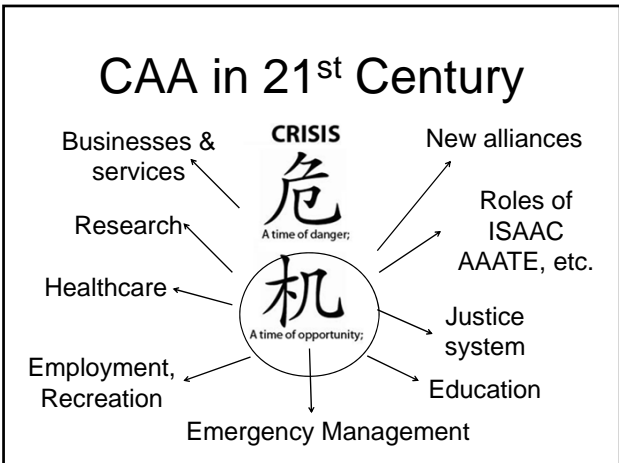
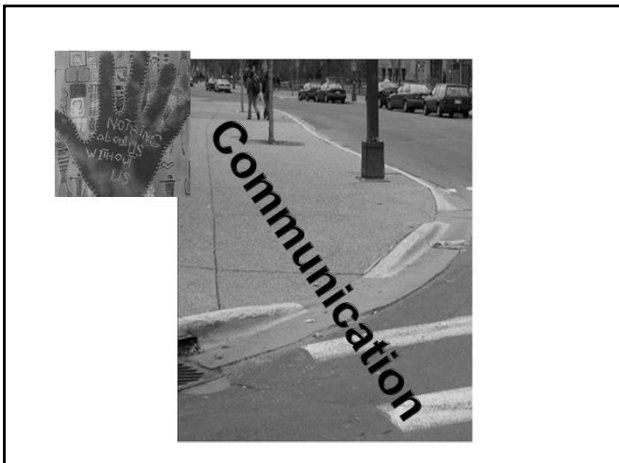
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### Communication Access for All

Access to Justice for People with Communication Disabilities  
... one size does not fit all.

ISAAC 2014  
LSCOL

Legend for pie chart:  
 ■ SPANISH  
 ■ PORTUGUESE  
 ■ CHINESE  
 ■ HONGKONG/TAIWAN  
 ■ VIETNAMESE  
 ■ JAPANESE  
 ■ KOREAN  
 ■ HAWAIIAN  
 ■ CANTON DIALECT  
 ■ FRENCH  
 ■ HINDI  
 ■ OTHER

### Example: Research

#### Community Businesses, Services, Organizations, Agencies

- Government Services
- Health Care Services
- Disability Services
- Emergency Services
- Transportation
- Stores
- Professional Services
- Restaurants, coffee shops, bars
- Recreation / Leisure
- Political / Civic events
- Educational Services
- Religious Services
- Personal Services
- Other....

**SURVEY**

- Individuals with complex communication needs (CCN)
- Service providers who support people who use augmentative and alternative communication (AAC).

(Collier, Blackstone & Taylor, 2012)

### Types of communication access barriers

- Face-to-face communication (expression and comprehension of spoken language)
- Telephone communication
- Text and print based communication
- Internet, email, and social media communication
- Written communication and
- Communication in groups.

### Access to

- Government Services
- Health Care Services
- Disability Services
- Emergency Services
- Transportation
- Stores
- Professional Services
- Restaurants, coffee shops, bars
- Recreation / Leisure
- Political / Civic events
- Educational Services
- Religious Services
- Personal Services

Figure 1: Percentage of Survey Respondents who Felt Each Type of Organization Could do a Better Job When Communicating with People who have CCN

(From Collier, Blackstone, & Taylor, 2012)

### Community Businesses, Services, Organizations, Agencies

### Communication Access Now: CAN Project

Directed by Barbara Collier

- Surveyed individuals with CCN
- Identify where need to communicate, how prefer to communicate
- Identify communication barriers
- Develop guidelines for businesses, organizations and agencies in Canada

Funded by Canadian Government

### Example Business

#### SCOPE in Australia

good communication is good business  
communication aid available here

<http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccess>

English, Vietnamese, Chinese-Mandarin

## Communication Access Now Project



<https://www.youtube.com/watch?v=gBBpMp2S4A>

Businesses, organizations and essential services  
2013-2015

CDAC) Communication Disabilities Access Canada

Communication Access
Videos
Communication Access
People with Communication Disabilities
Quotes
Communication Access Symbol
Communication Access Laws
Communication Access Rights
Six things to know
Useful Links



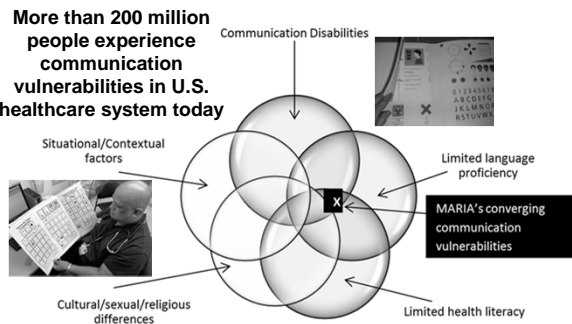
## Communication Training video [www.cdac.ca](http://www.cdac.ca)



## Example Health Care Patient Provider Communication

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

More than 200 million people experience communication vulnerabilities in U.S. healthcare system today



## Healthcare Continuum

- First Responders
- Emergency Rooms
- ICU's
- Acute Care Hospital
- Dr's Office/Clinic
- Rehabilitation Hospital
- Nursing Home
- Home Health
- Hospice

## Expectations: Typical PP Interview

- Between general practitioner and person without a disability
  - 20 minutes in length (Mann et al., 2001).
- Patient typically has 23 seconds to communicate concerns before being interrupted by the doctor.
  - Marvel et al. (1999)

## Health Disparities

- Result from barriers (race, ethnicity, gender, education, income, geographic location, disability status, and sexual orientation, other inequities)
- Disproportionately affect patients with communication difficulties.

(Patak, Wilson-Stronks, Costello, Kleinpell, Henneman, Person & Happ, 2009; Bartlett, Blais, Tamblin, Clermont & MacGibbon, 2008).

## Poor patient-provider communication can cause:

- Serious medical missteps
- Delayed healthcare utilization
- Increased healthcare utilization
- Increased costs
- Poor patient outcomes
- Reduced patient satisfaction  
(The Joint Commission, 2010ab; Divi, Koss, Schmaltz & Loeb, 2007)

## Communication Vulnerable Patients

### MORE LIKELY TO

- Be hospitalized
- Experience medical/physical harm, e.g., drug complications
- Leave hospital against medical advice
- Be intubated if asthmatic
- Have increase costs
- Delay care
- Receive a diagnosis of psychopathology

### LESS LIKELY TO

- Adhere to recommended medication regime
- Report abuse
- Access and use medical care
- Return for follow-up appointments after Emergency Room visits
- Be satisfied with care

Role of AAC strategies, techniques and technologies in patient-provider communication for individuals who are “communication vulnerable”



## What is “Effective Communication”?

“the successful **joint establishment of meaning** wherein patients and healthcare providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood”

(The Joint Commission, 2010b, p. 91 ).



## Joint establishment of meaning

“We must shift our focus from the specific deficits of an individual. It is conversations that are impaired, not the interactants.”



Wilkins, 2004; Blackstone, Williams & Wilkins, 2008

## Effective patient-provider communication

- Increases the likelihood that:
  - patients' problems are **diagnosed correctly**
  - patients understand **and adhere to recommended treatment regimens**
  - patients (and their families) **are satisfied** with the care they receive

(Wolff, Lehman, Quinlin, Hoffman, 2008)

- Is increasingly viewed as **an essential component** of quality healthcare and patient safety as well as **the basic right** of every patient.

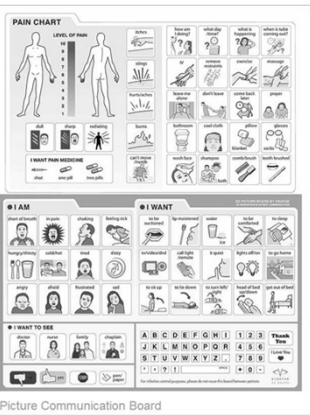
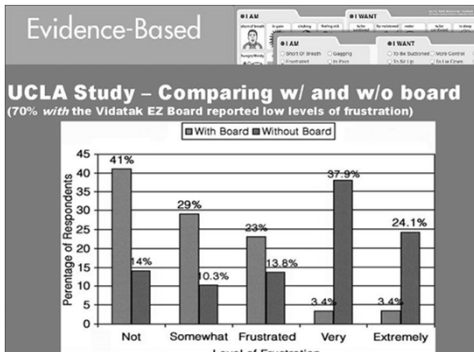
(Ethical Force Program Oversight Body, 2006; The Joint Commission, 2010, new ASHA mission statement)

## Example

Vidatak EZ Board



## Patient's level of frustration with/without board



VidaTak Boards for use in ICUs with children

John Costello, Children's Hospital Boston

## On The Spot

Debby McBride & Juli Pearson

Table II. Some items from the On The Spot Communication Tool Kit

Pocket folder & accessories	Magazine page	Clip board	Dry erase board
Lightweight and easy to hold. Sturdy. Useful when being used in a wheelchair.	Relays text to patient, can read if blurry or unreadable.	Sturdy paper, communication display, forms, instructions, etc. Has helpful tips on the back.	Wipeable surface. Supports communication and expression. Has helpful tips on the back (shown above).
Picture communication board in English/Spanish	English/Spanish cards	Health care communication board tablet	Vidatak EZ communication boards
Printed messages, symbols, words, pain scale and alphabet.	16 cards with words/words and pictures in English and Spanish, e.g. comfort, orientation, pain, etc.	Printed messages, symbols, words, pain scale and alphabet. English only.	Print to specific message. Has pain scale, alphabet and more. Available in 17 languages and system board.

## COMMUNICATE

### A UIHC Initiative December 2013

Goal:

1) Enhance bedside communication and reduce adverse events  
Strategies:

- 1) Raise awareness of the need to effectively communicate
- 2) Alert everyone to the patient's communication needs/barriers
- 3) Low Tech Communication Tools available at all beds
  - a) Adapted Switches/Nurse call
  - b) Writing Tablets
  - c) UIHC Basic Communication Boards
  - d) UIHC Bilingual Communication Boards
  - e) Specialty Communication Boards for doing assessments
- 4) High Tech Communication Devices via consult
- 5) Training Materials

<http://www.youtube.com/watch?v=w9rgNQ3R1sk>



Assistive Devices Lab at The University of Iowa

Health Passport

Communicating with Patients who have Speech/Language Difficulties


Guidance for Medical & Nursing staff

www.healthpassport.co.uk  
www.communicationmatters.org.uk/page/focus-on-download

## Widgit Health


<http://www.widgit-health.com/>

**Products**




Ready-made communication books & symbol software

**Downloads**




Documents for download and printing

**Beidote Messages**  
Developed in association with the Patient Provider Communication Forum, Central Coast Districts' Partnership and St. George's Hospital  
An app for patients, carers and visitors. Available on 20 different languages



**Outgoing information**  
Available **FREE**  
• Register as  
• Request Letter  
• Download all languages  
• Receive Messages App  
• Receive Messages Letter  
• Download Internet Language Links

Living able to communicate with someone quickly and clearly when they are in a health emergency is vital to saving lives.  
In routine healthcare, clear communication improves the effectiveness of diagnosis and treatment, leading to quicker and more successful recovery.  
By providing communication support, Widgit Health aims to improve the inclusion of patients, especially those who have a communication need.




Communication is a complex activity on the edge of all professional systems, and for patients and providers alike. It is a complex activity that requires a range of skills and resources. In emergency settings, a person's ability to communicate is critical for their safety and the safety of others. Widgit Health aims to improve the inclusion of patients, especially those who have a communication need. This is achieved through the development of communication support materials, such as the Beidote Messages app. This app is available in 20 different languages and is designed to be used in a range of settings, including hospitals, community care, and home care. The app is designed to be used by patients, carers, and visitors, and is available for free download. The app is designed to be used in a range of settings, including hospitals, community care, and home care. The app is designed to be used by patients, carers, and visitors, and is available for free download.

## Patient-provider website

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

- Policy statements
- Examples of materials
- Articles
- Stories



**Communication**

**About PFC**

The Patient Provider Communication Forum is a national and international effort to promote information sharing, cooperation and collaboration among individuals who are concerned by ongoing improvements in patient-provider communication across the entire health care continuum: from a doctor's office, emergency room, clinic, ICU, acute care and rehabilitation hospital, home health services and beyond.

Members of the group bring together a range of perspectives and experience in the area of patient-provider communication. The group works to share knowledge and resources and to raise awareness of both the practice and policy needs of the need to improve existing communication barriers and to increase communication across health care settings.


The Patient Provider Communication Forum seeks to achieve shared learning about patient-provider communication through:

- monthly conference calls among participants,
- an interactive website to share resources and tools and to seek feedback and opinions from the field,
- collaborative projects such as white papers, presentations and research studies that interest the areas of interest and experience of group members,
- Special interest concentrations about topics such as: emergency preparedness, intensive care units (ICU), the Safe Communication Program Materials related to effective communication, cultural competence and patient-centered care and information about specific populations and/or healthcare settings.

## Example Justice System CDAC in Canada

- Legal system
- Justice
- Abuse prevention
- Transition to adulthood
- Conflict Resolution
- And so on. . .

<http://www.access-to-justice.org/>



**Police, legal and justice services must be communication accessible.**

**Communication Access to Justice**

For many people with speech and language disabilities, effective communication within a legal/ public context means having a communication intermediary to assist with key-voice communication. In 2013, with funding from Department of Justice Canada, Victim Fund, CDAC is:

- Piloting a training program for communication intermediaries based on national standards of practice
- Setting up a roster of communication intermediaries
- Developing information and resources for people with communication disabilities and end-users of the services (e.g. police, legal and justice professionals)
- Supporting provincial governments across Canada to explore collaborative ways to implement communication intermediary services in their areas

## Institute on Disabilities – Temple University

### Augmentative and Alternative Communication (AAC) AAC Vocabulary

- Vocabulary Sets: College Life, Emergency Preparedness, Employment, Health Care, Transportation
- Vocabulary Set: Personal Assistance Service
- Vocabulary Set: Reporting or Telling about Being a Victim of a Crime
- Vocabulary Set: Sexuality, Intimacy and Healthy Sex

## Example Communication Supports/Assistants/Intermediaries



**Training?**

**Regulating? Licensing?**



## The role of Human Supports for Communication Access

- Communication assistants
  - Sign-language Interpreters for the deaf
    - Trained and paid
  - Intervenor services for the deaf-blind
    - Trained and paid
  - Professional readers for the blind
    - Trained and paid
- Communication assistants for people with CCN
  - Rarely trained, rarely paid
  - Communication partners
  - Communication facilitators

## Finland, Sweden & Canada

### Sweden –

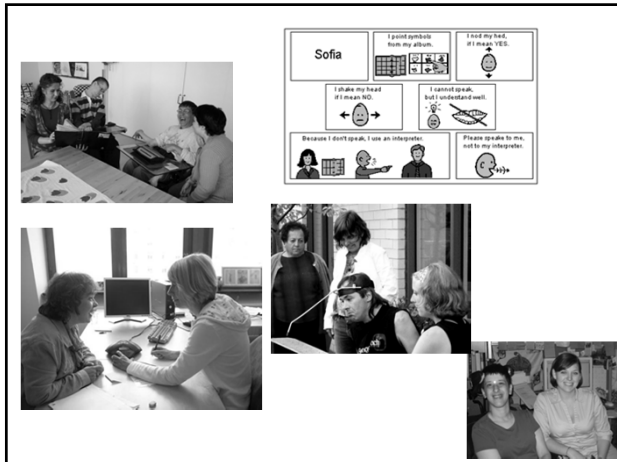
- SSIS interpreter services for people with CCN since 1986
- Funded by Swedish Health Dept
- Coursework for SSIS interpreters
- SSIS for people with aphasia: Results of a study

### Finland -

- SIS Interpreter services for people who have difficulty speaking or understanding speech, either spoken or written
- No cost to individual
- 180 hrs per year
- At school, work, community
- Trained to translate/interpret /support

## Canada

- Communication Assistant project
- Explore use of CA support for adults who rely on AAC
  - 9 individuals with CCN
  - 13 Communication assistants
- Participant training – 30 hours
- Centralized services
- Results (see page 11, ACN, vol 20, #3, 2008)



## Example: Supporting CAA in Developing Areas

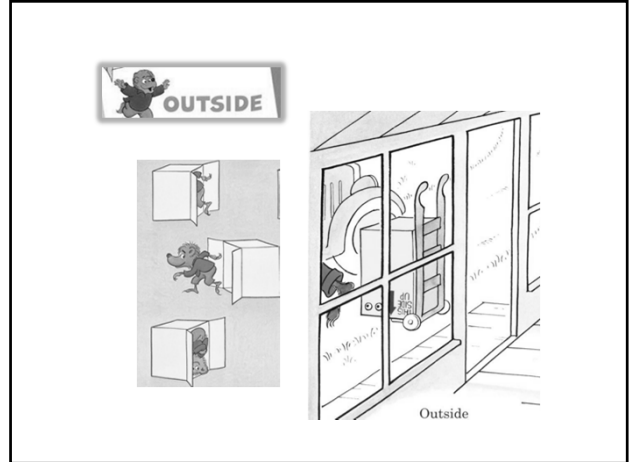


## EXAMPLE: COMMUNICATION ACCESS IN EMERGENCY AND DISASTER SCENARIOS



## Who is vulnerable?

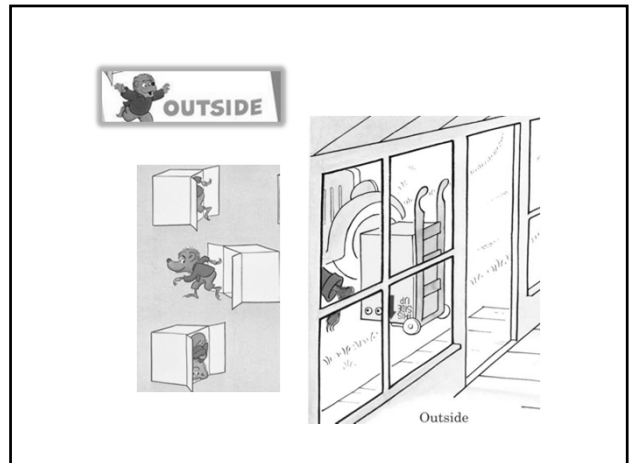
- People with speech, hearing, vision impairments
- People with significant cognitive challenges
- People with mobility limitations
- People with 2<sup>nd</sup> language issues
- People with limited understanding of spoken language
- The very young
- People who **are sick/ill**
- People under severe stress or who are confused
- People who do not have access to tools/ supports they need



I'm Pam Kennedy.	I can't speak but can understand you.	They're looking for a place for me.	Jessie needs to go out.	Jessie is out of food.	Are access roads still flooded?	Any new updates?	did	and	backside
Please ask questions when you need to.	I have family in Bismarck.	I don't know how much I lost yet.	Jessie needs water.	My chair needs to be charged.	Any refugees found homes since I was sent?	hurt, hurts	shoulder	chest	thigh
I have cerebral palsy and epilepsy.	My vital info is on my PC. I'll get it.	The basement was flooded.	Jess is confused, stressed out.	Has anyone else been found?	Has anyone called regarding my status?	head	arm	ribs	knee
I, my	need	wrist splints	amfeet	nauseous	dizzy	eyes	wrist	stomach	shin
pen	morning meds	pain meds	like	pain meds	swelling	ear	hand	back	ankle
paper	evening meds	inhaler	seizure	headache	double vision	nose	finger	waist	foot
yes	no	OK	Oops!	Wait.	computer	mouth	left	right	bad, badly

A	B	C	D	E	F	G	Hi	Bye	How are you?
H	I	J	K	L	M	N	Sorry!	Wait.	please
O	P	Q	R	S	T	U	Thank you!	You're welcome	listen
V	W	X	Y	Z	Space	.	blanket	pillow	computer
0	1	2	3	4	5	6	paper	pen	a drink
7	8	9	Jessie	I me, my	you, you!	he, him, his	oops!	OK	soup
yes	no	know	don't know	want need	help	bathroom	seizure	?	I can't swallow that.

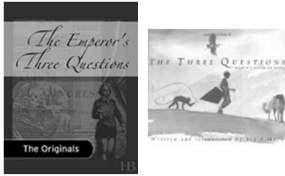
inemy	you/your	dog	soldier	family	friend	man he	woman she	mom	dad
home	present	happy	done	eat	drink	go	hi/bye	arm	loud
want	past	sad	move	sandwich	soda	question	thank you	hand	help
don't	future	angry	chair	soup	water	front	on	head	stink
toilet	hurt	afraid	bed	bread	back	down	off	stomach	yuck
good	wrong	bad	pillow	more	inside	up	sick	foot	very
yes	wait	no	blanket	flood	outside	okay	medicine	leg	next page



**Augmentative and Alternative Communication (AAC)**

Communication Access  
**for All (CAA)**

**The Three Questions Tolstoi**



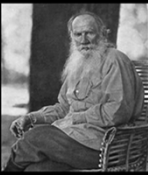
- Most important time?
- Most important person?
- Most important thing to do?

**"The Three Answers"**




The most important time is  
**"Now"**

The most important person is  
**"The one you are with"**

The most important pursuit is  
**"To do good to that person"**



Leo Tolstoy

**This is where rubber hits the road!**



Recognize new opportunities  
Get "Added value" out of our skills  
**A RIGHTS issue**





Use your skills in ways  
that make a difference



ISAAC Conference Lisbon  
July, 2014



***A conclusion?  
The place where you got tired  
of thinking.***

Stephen Wright

Thanks for your attention and  
participation



- Be Brief
- Be Brilliant
- Be Seated