

Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

**Non-Negotiable AAC Supports
for Persons with
Significant Intellectual Disabilities
Across the Age Span**

John M. Costello
Speech-Language Pathologist
Augmentative Communication Program
Children's Hospital Boston



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Agenda

1. How I became focused on this topic
2. Philosophy
3. Profiles of communicators
4. Basic considerations for assessment - positioning and motor access
5. Discuss self-determination
6. Discuss non-negotiable supports



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Philosophy



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**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**


**All People
Communicate**



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ha
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m: **BREATHING** 3
th: ...
ca
br
relevant to communication.
Miranda, Pat 1992



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**“Ability is of little
account without
opportunity”**

- Napoleon Bonaparte



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Disabilities**

**Perhaps the only real prerequisites
to communication are in the area
of communication *opportunity***

- Mirenda and Iacono, 1990


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**“Our Lives Teach
Us Who We Are”**

Solmon Rushdie

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Shoe Test

Putting yourself 'in the shoes' of another

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Purpose of Communication (Light, 1988)

- Communication of needs and wants
- Information transfer
- Social closeness
- Social etiquette

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Communication function

The function is the outcome the learner's behavior produces

AAC for Individuals with moderate to severe disability, Johnston, et al. 2012

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Exercise (choice task)

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Wh- question acquisition:

Question form	Age acquired	concept
Yes/no	2.0	
What + be	2.0	identify
What + do	2.6	action
where	2.6	location
why	3.0	Cause/effect
How (many, soon, big, etc.)	3.6 - 5.6 (size)	Manner/description
When	5.6	time
Which	5.6	selection

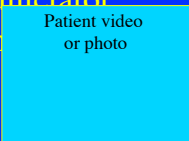
Profiles of communicators

- Emerging communicators
- Context-dependent communicators
- Independent communicators

Emerging Communicator Discussion

- 37 year old man
- Lived in an institutional setting
- Some long-term staff; many short-term staff
- Reported to have severe intellectual disability
- Communicates primarily through interpretation of his behavior by familiar listeners

WHAT IS POTENTIAL COMMUNICATION
Assessment/intervention and goal?



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EMERGING COMMUNICATOR

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- Non-intentional communication: not produced for benefit of others

(child cries because is in discomfort)

As opposed to....

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Communicative intent:

- deliberately pursuing a goal produced for the benefit of others (signaling behavior in which the sender is aware a priori of the effect that a signal will have on his listener – Bates, et.al)

child cries after injury only after an adult/parent acknowledges the child.

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Profile 1 Pre-symbolic/Pre-intentional

- **Likely candidates**
 - Children and adults with extreme cognitive impairment
 - Often accompanied by neurological, sensory and/or physical complications
- **Typical characteristics include**
 - Non-intentional communication
 - requiring interpretation of behavior and affect from informed caregivers
 - Not demonstrating responsiveness to symbolic materials
 - Not demonstrating awareness of cause and effect

Patient video or photo

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Communication Objectives (Profile 1)

- **Objective**
 - Understand and identify means of communication (through caregiver interpretation)
 - Develop opportunities for consistent learning to foster communicative intent
 - Develop understanding of cause / effect
 - Determine Preferences
- **Recommendations**
 - Complete communication profile
 - Introduce Active Stimulation opportunities
 - Support incidental learning opportunities
 - Identify communication and learning objectives to focus on behavior regulation and joint attention

Patient video or photo

Children's Hospital Boston From Howard Shane 2002

Behavior regulation

- Requesting an object, requesting actions and protesting.
 - Protoimperative: term used to refer to early emerging behavior regulation communicative acts
 - Example: look at item and then reach for item and vocalize, then shift gaze toward partner. Once partner attention achieved, looks at referent and repeats action.

AAC for Individuals with moderate to severe disability, Johnston, et al. 2012 21

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Joint attention

- Interested in directing a communication partner's attention to an object
- Protodeclarative: early developing joint attention. Includes commenting on actions, requesting information, providing clarification and transferring (placing an object in another's hand)


AAC for Individuals with moderate to severe disability, Johnston, et al. 2012
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Profile 2

Transition to Symbolic Representations

- Likely candidates
 - Children and adults with extreme cognitive impairment
 - Often accompanied by neurological and physical complications
 - Similar to Group 1, but have slightly higher Psycho-linguistic performance and some representational abilities
- Typical characteristics include
 - Transition to symbolic representational material
 - Transition to symbolic communication
 - Continue to require interpretation of communicative intent

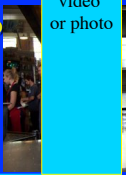
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Communication Objectives (Profile 2)

- Objective
 - Understand and identify means of communication (through caregiver interpretation)
 - Develop communicative intent (teach manding)
 - Support learning social interaction/communication
 - Develop understanding of cause / effect
 - Improve symbolic representational ability (3D -> 2D)
 - Determine Preferences
- Recommendations
 - Complete communication profile
 - Identify communication and learning objectives
 - Continue Active Stimulation Program
 - Provide incidental opportunities

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Social interaction

- The learner's attempt to attract or maintain another person's attention to him or herself.
- Examples include: greetings, showing off, requesting a social routine (example: Peekaboo), calling, acknowledging the comments produced by another and expressing mood or feeling.

AAC for Individuals with moderate to severe disability, Johnston, et.al. 2012
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**Profile 3
(Symbol Based)**

- **Likely Candidates**
 - Children with neuromuscular disorders (i.e., Cerebral Palsy)
 - Children and adults with autism or PDD
 - Children and adults following head injury
 - Children but mainly adults with aphasia
- **Typical characteristics include**
 - Demonstrates intentional communication
 - Achieved (or high potential to achieve) some level of representation (Photo, drawings, graphical metaphor, etc...)

From Howard Shane 2002
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**Communication Objectives
(Profile 3)**

- **Objectives**
 - Determine representation knowledge
 - hierarchy -- levels of representation
 - communication display grid Vs. graphical metaphor
 - hybrid model
 - Expand functional communication (pragmatics)
 - Develop Pre- literacy skills
 - Expand independent communication

From Howard Shane 2002

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What is needed to be an Effective INTENTIONAL Communicator?

Motivation to communicate: a desire to interact with the world, a desire to control the way the world interacts with oneself.

A preference: A preference to have things in a particular way versus being content with any situation.

Intentionality: being motivated enough to have things in a preferred state that one will purposefully do something to obtain that state, having a purpose to an action.

A representation: Understanding that an item/action represents a specific item. Initially, understanding that an object is something one can act upon. Next, one can act on an object and get a similar.

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What is needed to make a 'choice'

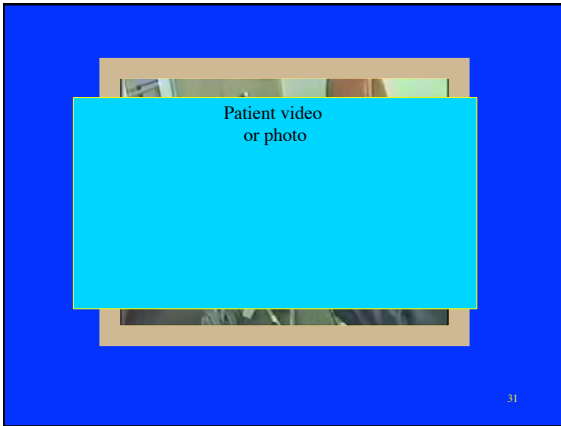
- **Orients:** looks towards a source or a change in movement or sound produced within a field but not within direct line of gaze.
- **Attending:** maintains visual attention to an interesting display for at least five seconds.
- **Tracks:** visually follows horizontal or vertical path of interesting objects.
- **Alternates attention:** shifts attention between two interesting objects or displays spaced widely apart****is needed to effectively make choices but may not always be obvious that the person can do it*****

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- **Reaches and captures:** reaches and captures object of interest held in front of student *** alternate access must be considered for persons with significant motor impairment.***
- **Captures and manipulates:** grasps and acts on interesting objects held within reach. (grabs it and does something with it) *** alternate access must be considered for persons with significant motor impairment.***

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or photo

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Non-negotiable:
non-ne-go-tia-ble
adj.
1. Difficult or impossible to settle by arbitration, mediation, or mutual concession; a nonnegotiable demand.
2. Nonmarketable
American Heritage® Dictionary of the English Language, Fourth Edition

Something that is a must - can not be compromised

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Non-Negotiable Supports

- **Communication Profile**
- **Choices**
- **Engineering for Participation**
- **Incidental Communication and Social Connectedness**
- **Providing Information through Multimodal strategies**
- **Support use of communication strategies and technology**
- **Support Effortless Success in the Community**

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**“As long as people
consider my brain useless
and my facial expressions
and sounds meaningless,
I was doomed to remain
voiceless”**

Ruth Sienkiewicz-Mercer

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Assessment - What is it?
It is NOT to identify the deficits
It IS to identify the potential opportunities

- Ecological based: Assessment of settings in which person participates (or could/should participate) to:
 - identify the opportunities available for communication
 - Identify adaptive and AAC techniques to support participation and success

Inventory of the 'GAPS'

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Communicative Competence

- Linguistic
- Operational
- Social
- Strategic

Toward A Definition of Communicative Competence
Janice Light, 1989, AAC V5, #2

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LANGUAGE IS BOTH EXPRESSIVE AND RECEPTIVE


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Spontaneous Combustion of Skills

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Reminding ourselves of what we
already know

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Considerations during assessment

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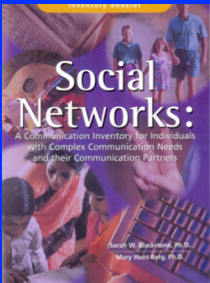
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Important assessment consideration:

Communication Partners and different strategies used with different partners

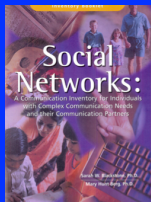
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Social Network



1. Life Long Partners
2. Close Friends and relatives
3. Acquaintances
4. Paid workers
5. Unfamiliar people

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- Emerging Communication Group
- Context Dependent Communication Group
- Independent Communication Group

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Circle of Communication Partners Orientation Forms

Use this blank form and the example here to remember the concept of Circle of Communication Partners (CCP) to the individual being interviewed. You may wish to copy and laminate this form. See page 8 of Assessment Checklist and page 24 of Manual.

LEGEND

- 1 1st circle - self
- 2 2nd circle - family
- 3 3rd circle - neighbors/peers
- 4 4th circle - school/workplace
- 5 5th circle - broader community

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- facial expression/body language
- gestures
- vocalizations
- manual signs/sign language
- speech
- writing/drawing
- nonelectronic communication board/book
- simple communication device
- complex communication device
- special communication software used on a computer
- phone
- email
- other modes of communication _____

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WHO and How many

How?

1st Gestures
2nd Gestures
3rd Gestures
4th Complex VOCA
5th Gestures

1st Gestures
2nd Gestures
3rd Gestures
4th Gestures
5th Phone

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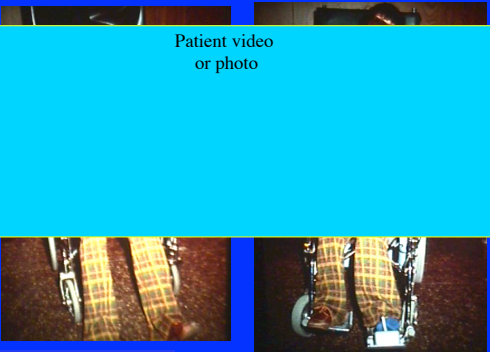
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Seating and Positioning

- Breath support for vocalizations/speech production
- Stability for consistent and reliable control site/access strategies
- Range of motion
- Eye contact/socialization
- Comfort and security decreases fatigue level


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Common Control Sites and Performance Factors


Peggy Barker, M.S.
Rehabilitation Engineer

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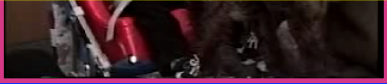
Hands

Potentially large range and fine resolution


<u>Advantages:</u>	<u>Disadvantages:</u>
<ul style="list-style-type: none">• In field of vision• Greater sensation in hands• Easier to mount/stabilize input or device	<ul style="list-style-type: none">• Reflective posturing forward• Eye-hand inseparation• Suspended arm versus supported arm• Release difficulties• Triggers reflex patterns

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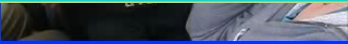


Daniel

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Patient video or photo



Teaching to 'point'

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Patient video or photo



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Head

Potentially large range/fine resolution

Advantages:

- Less movement required
- Less visual distractions
- Easy to position at least three switches
- May encourage upright position

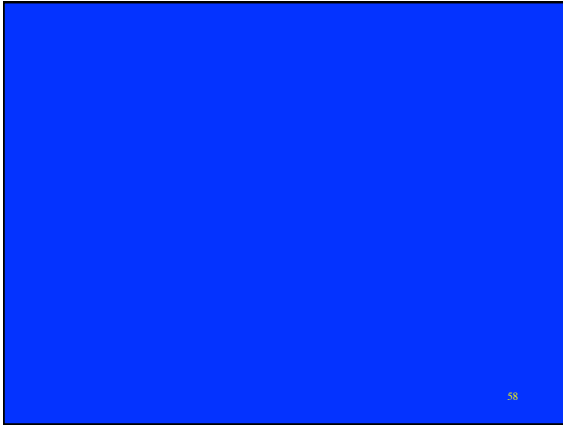
Disadvantages:

- ATNR response
- Eyes may shift toward switch
- May not be able to separate head and eye movement
- Headrest may interfere

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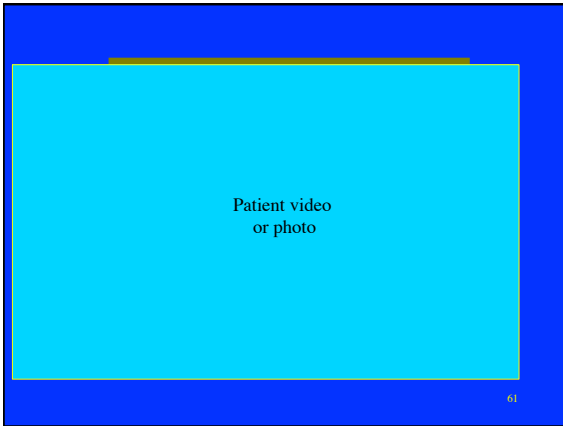
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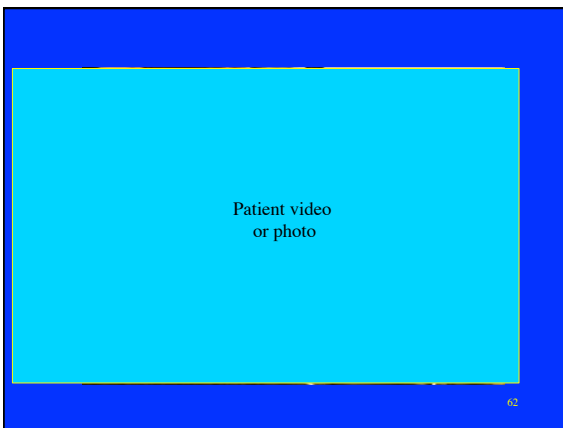


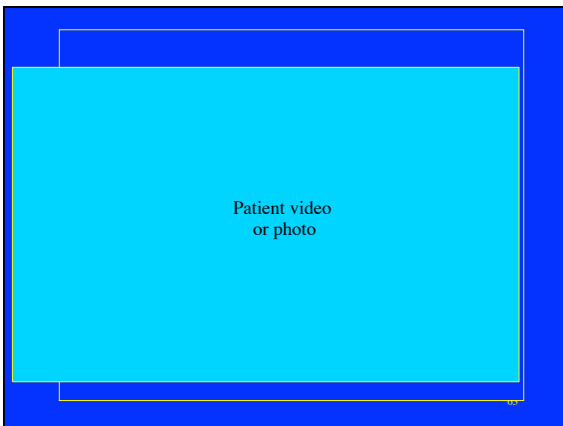




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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Feet
Large range and gross resolution

Advantages:

- Low profile look
- Potential for proportional control

Disadvantages:

- May be visually distracting to communication partner
- May be difficult to mount/position
- Resting place/stabilization of foot may be problematic
- Unintentional activation when excited

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Patient video
or photo

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Patient video
or photo

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Arms/Elbows/Legs/Knees
Small range with gross resolution

Advantages:

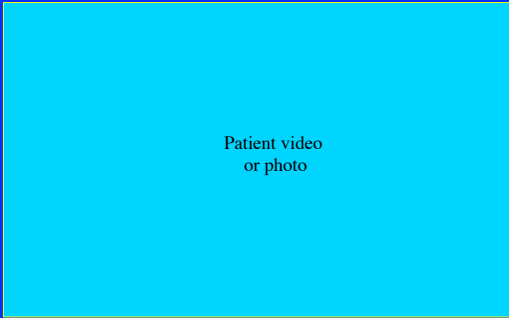
- Less movement required
- Less visual distraction
- Elbow increases trunk and head extension
- Easier to stabilize
- Low profile


Disadvantages:

- May be difficult to do unilaterally
- Person may rest on switch
- Unintentional activation when excited
- Reflex movement can sabotage

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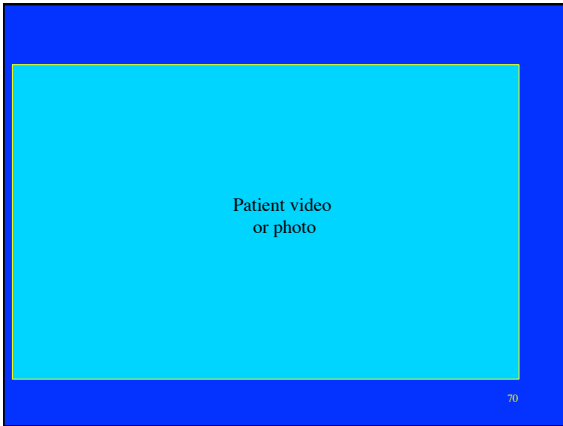
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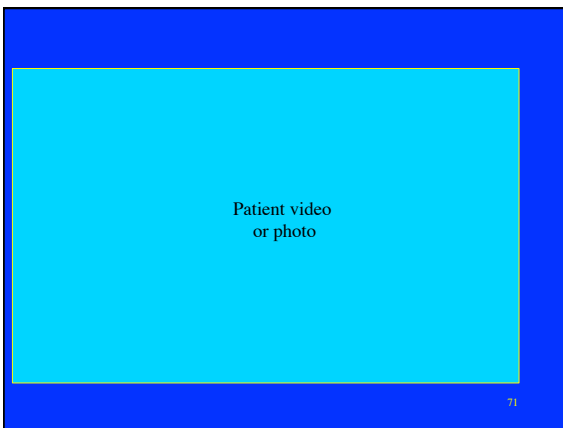
Effective switch control:

- Select
- Release
- Wait

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Disabilities**







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“Children are viewed as active participants who learn to affect the behavior and attitudes of others through active signaling and who gradually learn to use more sophisticated and conventional means to communicate through caregivers’ contingent social responsiveness.” -

-Kublin, Wetherby, Crais and Prizant, 1998

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Therefore, development is influenced by a child’s ability to produce readable signals, a caregiver’s ability to respond appropriately to the child’s signals and the routinization of such patterns.

-Kublin, Wetherby, Crais and Prizant, 1998

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Does this apply to the person with significant intellectual disability?

1. d **1. Person does SOMETHING (produces a signal which may be intentional or unintentional)** lity to

2. **2. Communication Partner responds to that behavior as meaningful** ately

3. Communication partner is consistent in responding to and treating signal as meaningful

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SUGGESTS THAT WE SHOULD MORE CLOSELY ATTEND TO:

- THE GOALS OF COMMUNICATION INTERVENTION,
- THE CONTEXT AND
- THE CONSISTENCY OF PRESENTATION/EXPECTATION

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Communication is a basic Human Right

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“Communication is any act by which one person gives or receives information about that person’s needs, desires, perceptions, knowledge or effective state. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic form, and may occur through spoken or other modes.”

Guidelines for meeting the communication needs of persons with severe disabilities - National Joint committee for Communication Needs of Persons with Severe Disabilities.

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Communication Bill of Rights
1992

National Joint Committee for the
Communication Needs of Persons
with Severe Disability

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Each Person has the right to:

- Request desired objects, actions, events and people
- Refuse undesired objects, actions, events
- Express personal preferences and feelings
- Be offered choices and alternatives
- Reject offered choices
- Request and receive another person's attention and interaction

continued..

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Each Person has the right to

- Ask for and receive information about changes in routine and environment
- Receive intervention to improve communication skills
- Receive a response to any communication, whether or not the responder can fulfill the request.
- Have access to AAC services and other assistive technology services and devices at all times.

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Each Person has the right to

- Be in an environment that promotes one's communication as a full partner with other people, including peers
- Be spoken to with respect and courtesy
- Be spoken to directly and not be spoken for or talked about in the third person while present
- Have clear, meaningful and culturally and linguistically appropriate communications.

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Service Delivery influenced by:

- **Focus on Self Determination**
- **Massachusetts DMR QUEST Tool**

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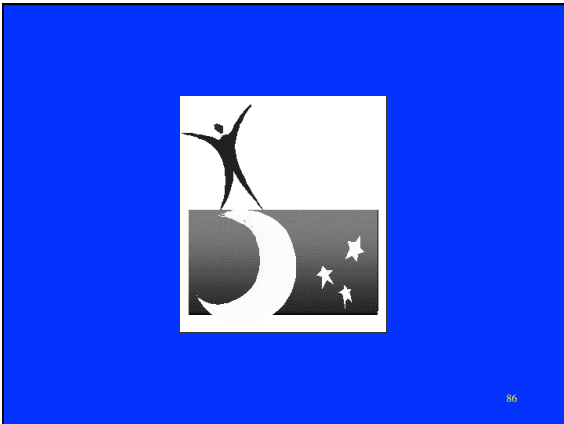
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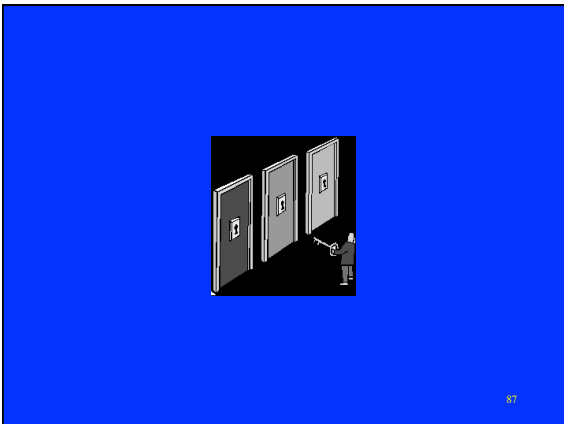
Self determination in visuals...

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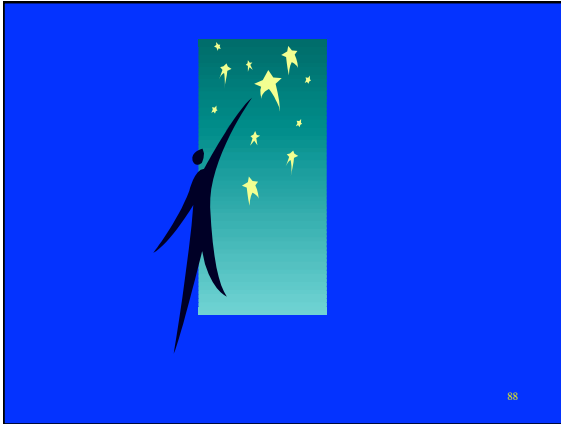
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Persons with Significant Developmental
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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities



What is Self Determination?

“It can be as simple as being able to chose extra sauce on your pizza or as complex as choosing to live in your own apartment with the services and supports you need.”


North Carolina Self Determination Leadership Network
www.intrex.net/ncsdln/whatisselfdetermination.html

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Self Determination - *The ARC*

Position (www.thearc.org/posits/selfdetpos.html):

- **People must have opportunity to acquire skill and develop beliefs that enable them to take greater control**
- **All people, including those with significant disability, can express preferences and use those preferences to make choices.**
- **People must:**
 - Be treated with dignity
 - Have wide range of typical experiences
 - Be supported to make decisions that impact their life
 - Have opportunity to self advocate
 - Have control over financial resources
- **Others must support people with mental retardation to have greater control of their lives**


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ARC's Functional Model of Self-Determination

- self determination cannot be defined as a specific response (set of behaviors) because any behavior can be an expression of self determination.
- ...people who are self determined are viewed as such because of the way they act, and the purpose of their actions.
- Wehmeyer, 98

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Maladaptive behavior or standing up for own rights and 'negotiating' with the tools available.

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Exercise:
Need three volunteers

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Self determination may develop/be supported by:

- achieving developmental milestone
- opportunity to assume control as a result of
 - environment that supports control and choice
 - frequent experiences of choices and control

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Massachusetts DMR Quality Enhancement Survey Tool (QUEST)

Five quality indicators:

- Rights and Dignity
- Individual Control
- Social Inclusion
- Personal growth and accomplishment
- Personal well being

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QUEST Tool


Designed to measure the impact of services on the life of individual's receiving services through Massachusetts DMR.

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QUALITY OF LIFE AREA #1: Rights and Dignity

OUTCOMES:

- People are Valued
- People's rights are affirmed
- People's rights are protected

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Outcome: People are valued

- A. Interactions are respectful of people
- B. People are supported to identify themselves as adults
- C. People are supported to take pride in themselves and their surroundings
- D. People live and work in setting that are typical of other members of the community

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EXAMPLES OF SUPPORT:

- A respectful tone of voice and adult language is used when speaking with and assisting people
- People are included in conversation
- Supports listen and respond when people express themselves
- People are described in positive and affirming ways which describe their abilities, not their disabilities
- The use of labels to describe people is avoided (e.g., behavior such as 'a runner')

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EXAMPLES OF SUPPORT (continued)

- Vehicles, signs, furnishing, equipment and materials promote people as valued, competent adults.
- People are supported to look their best
- Supporters encourage people to answer the door and telephone
- People's homes are situated in typical neighborhoods and do not have features that unnecessarily distinguish them from other homes in the neighborhood

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Outcome: People's rights are affirmed

- A. People and/or those supporting them understand individual rights
- B. People's rights are exercised in their everyday lives
- C. People receive the same treatment as other employees and receive comparable wages/benefits

EXAMPLES OF SUPPORT:

- Human rights training is provided
- People's family and guardians are informed of individual rights so they can support
- People do not have to ask permission to do routine things
- Areas of the house are not 'off limits' to people (e.g., staff bathrooms, etc.)
- Displays of data or information of a personal nature is not visible in commonly used areas at work or home (e.g., behavior charts, medication charts, diet plans).


Outcome: People's rights are protected:

- All interventions are the least intrusive and are based upon people's unique needs
- All interventions are included in a written plan
- All interventions are safely, accurately and consistently implemented.

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EXAMPLES OF SUPPORT:


- Less restrictive alternatives are always explored
- Data are collected on all interventions and target behaviors
- Changes are made when interventions reach the target goal
- There is a regular review of all interventions

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**QUALITY OF LIFE AREA #2:
Individual Control**


OUTCOMES:

- People are Understood
- People make choices in their every day lives
- People are the primary decision makers in their lives

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Outcome: People are Understood


- Supporters understand what people are saying
- Supporters use people's primary means of communication
- Supporters assist people to be understood by others

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

EXAMPLES OF SUPPORT:

- People's mode of communication is consistently used where they live, work and spend free time
- **Supporters consistently understand and are responsive to individuals' expression and non-verbal cues even when people have very limited ability to communicate their preferences and needs (e.g., gestures, facial expressions)**
- Supporters can communicate with individuals when they express themselves in different languages (e.g., Spanish, sign language)


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- Augmentative or assistive communication systems are used consistently and effectively when needed (e.g., TTY, communication board, computer augmented communication system)
- **People are supported to have ready, independent access to and support to use their communication devices and strategies**
- When needed, certified deaf interpreters used
- People receive support to understand verbal and written communication (e.g., letters from friends, employee handbooks)

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Outcome: People make choices in their everyday lives


- A. People make choices about their routines and schedules
- B. People make choices about work and household tasks for which they are responsible
- C. People spend their leisure time in personally satisfying ways

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

EXAMPLES OF SUPPORT:


- People choose when and what to have for breakfast, lunch, dinner and snacks
- People decide when and how to complete the household tasks for which they are responsible, taking into consideration the choices of the other people with whom they live
- People decide when to go to bed and get up in the morning and what to wear each day
- People are supported to change their routines

 Children's Hospital Boston 112

- People are encouraged to exercise spontaneity
- People are encouraged to build their interests and strengths into leisure activities and hobbies
- People are supported to learn what options and resources are available to them and choose how to spend their free time
- There is time and opportunity for people to get involved in activities such as pursue hobbies or their own choosing
- People make their own vacation plans

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- People are supported to make decisions about what work to do from among the work that is assigned to them and how to sequence their work assignments within the parameters of their job or work setting
- People make choices about where and with whom to take breaks and lunch
- People can go out to eat when time and money permit
- People are supported to decide when to use their vacation and personal time
- People's daily routines are tailored to their preferences
- There is time and opportunity for people to do activities and learn different things of their own choosing

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Outcome: People are the primary decision makers in their own lives

- A. People develop their personal goals
- B. People influence who provides their support
- C. People control important decisions about their home and home life
- D. People choose where they work or, if they choose not to work, people have other options that are meaningful to them

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EXAMPLES OF SUPPORT:

- Individuals are supported to be active participants in developing their own goals
- the exploration process includes information from others who know people well
- People have a say about who moves into their home.
- If people are dissatisfied with their current home or house mates, they are supported to make a change

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Quality of Life Area #3: Community and Social Connections

- A. People are integrated into their community
- B. People are connected with their community
- C. People have relationships

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


EXAMPLES OF SUPPORT:

- People have access to resources such as public transportation, places of worship, supermarkets, parks and other outdoor spaces
- People learn about and use local resources such as library, restaurants, theatres, etc.
- People use the same resources as both disabled and non-disabled people.
- People are supported to help out in their neighborhood, city or town.
- Supporters act as bridge builders to support community involvement
- People are supported to spend time with family, friends, co-workers
- People are supported to develop a social network that goes beyond people who are paid to support them.

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Quality of Life Area #4:
Personal Growth and Accomplishments

- People accomplish their goals
- People have autonomy
- People grow through their life experiences

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Examples of support:

- Strategies and supports are individualized and directly relate to people's goals
- Assistive technology is provided when people would benefit in order to support autonomy.
- Supporters are sensitive and take the time to communicate with people about day to day experiences and major events.

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

**Quality of Life Area #5:
Personal Well Being**

- People are safe at home and work
- People are free from harm
- People maintain good health
- People's funds are safe guarded

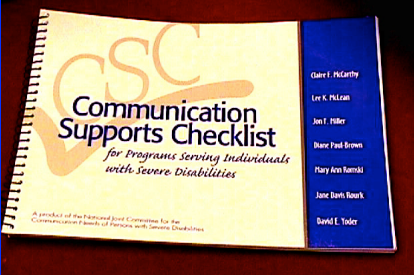
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Communication Participation Barriers
based on Participation Model
Beukelman and Mirenda (1988)

Opportunity Barriers:

- Policy √ segregation/limited use
 √ caseload/administrative
- Practice staff decision
- Attitude √ Macro-society attitude
 √ Micro-society attitude
- Knowledge

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Brookes Publishers
Baltimore, Maryland USA
- 1998

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Communication Bill of Rights

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions. These rights are summarized from the *Communication Bill of Rights* put forth in 1992 by the US National Joint Committee for the communication Needs of Persons with Severe Disabilities.


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Communication Bill of Rights

- Request desired objects, actions, events and people
- Refuse undesired objects, actions or events
- Express personal preferences and feelings
- Be offered choices and alternatives
- Reject offered choices
- Request and receive another person's attention and interaction
- Ask for and receive information about changes in routine and environment
- Receive intervention to improve communication skills
- Receive a response to any communication, whether or not the responder can fulfill the request
- Have access to AAC and other assistive tech services and devices at all times
- Have AAC and other AT devices that function properly at all times
- Be in an environment that promotes one's communication as a full partner with other people, including peers
- Be spoken to with respect and courtesy
- Be spoken to directly and not be spoken for or talked about in the third person while present
- Have clear, meaningful, and culturally and linguistically appropriate communications

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Communication Supports Checklist - review

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


INTERVENTION CONSIDERATIONS

- Do You Know Preferences
- Have You Considered Alternative Visual Presentations (Functional Vision Info)
- Are You Expecting Skill Without Opportunity To Learn
- Does Your Presentation Sabotage (Language, Manner Of Representation Presentation, etc.)

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Management of Sensory Impairment in Augmentative and Alternative Communication


Lloyd, Wasson, Blichak
Purdue University
ASHA Presentation, 1994

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Risk factors for vision and hearing impairment

- In-utero exposure to: Rubella, Cytomegalovirus, toxic drugs, untreated material syphilis, toxoplasmosis, Herpes, Diuretics
- Low birth weight
- Jaundice
- Meningitis
- Mental Retardation
- Exposure to toxic drugs
- Familiar disposition
- Prenatal anoxia
- Craniofacial anomalies
- Cerebral Palsy
- Head Trauma
- HIV infection
- Aging
- Genetic syndromes such as Down Syndrome Turner, Crouzons, Treacher Collins, Hurler's, etc.)


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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Practitioners involved in Assisting Persons Having Visual Impairment

- Pediatric Ophthalmologist
- Optometrist
- Low Vision Instructor
- Vision Educator
- Orientation and Mobility Instructor

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LESSONS FROM NEIL

also, impact on presentation of material such as do slower or lengthier so people with motor disabilities and processing difficulties can actually look and see!

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**HORIZONTAL
VS
VERTICAL**

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

CVI and severe physical impairment

- These characteristics include:
 - Color response: usually can see bright colors and may prefer single color objects
 - Movement response: use motion to gain attention; if it is stagnant it may not be seen
 - Latency of response: it may take time for vision to 'click in', requiring wait time. With increased consistent experience, wait time decreases.

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- Visual fields: may show distinct visual field preferences, may not use central vision at all
- Complexity: complexity of object or background may make using vision difficult. Competing auditory information (lots of verbal cues) may cause person to stop using vision all together.
- Visual motor responses: child may have significant difficulty performing multiple motor tasks including looking and reaching, looking and pushing switch, etc.
- Light gazing and non-purposeful gaze: competing light from window or overhead lighting will compete with visual attention to task.

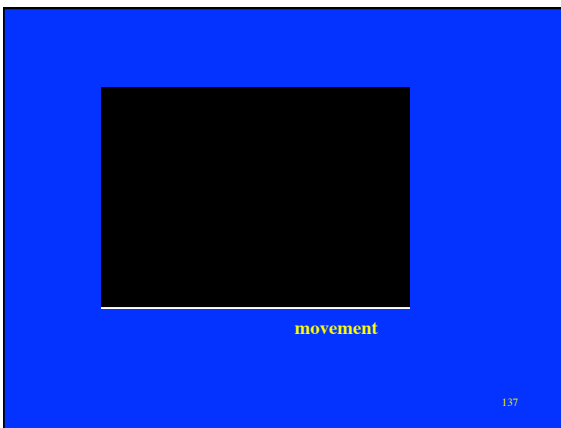
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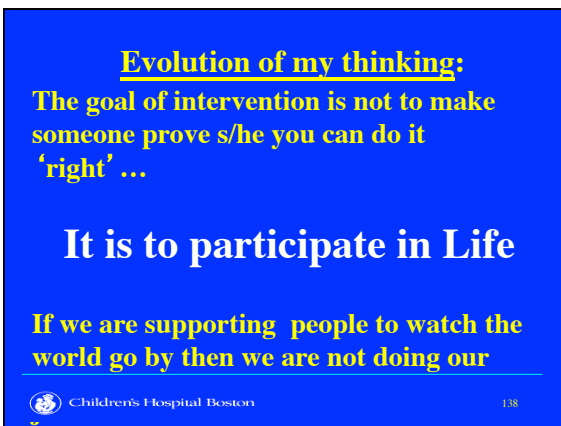
- Distance viewing: child has viewing success within a limited area and outward expansion may be supported over time.
- Visual novelty: may have difficulty viewing objects/materials that are new or do not have preferred features

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities









Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Evolution of support


- 1988: Bob will choose a preferred item from a field of three objects with 80% accuracy in three consecutive months of data collection.
- 1993: Bob will communicate his preference in at least three different situations daily with 80% accuracy in three consecutive months of data collection
- 1999: Bob will be supported to communicate his interests and needs throughout his day in all environments using a variety of strategies including object choice displays and simple speech output technology.
- 2001: Bob is supported to communicate his interests and needs...with data collected for three situations/three times per week, 80% of data collection per month

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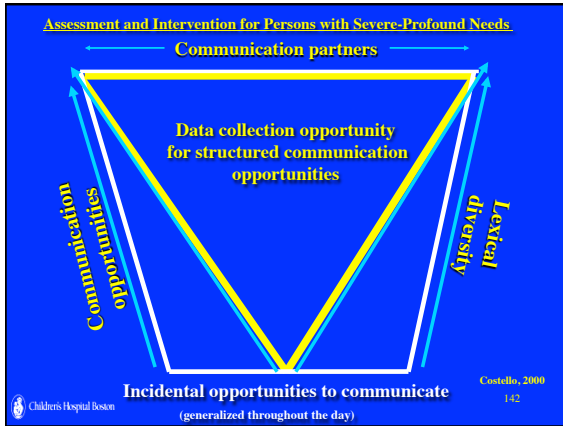
Does not mean that we abandon data collection, including types of prompts and supports, observations, choices, situations, name of supporter and date/time of interaction.

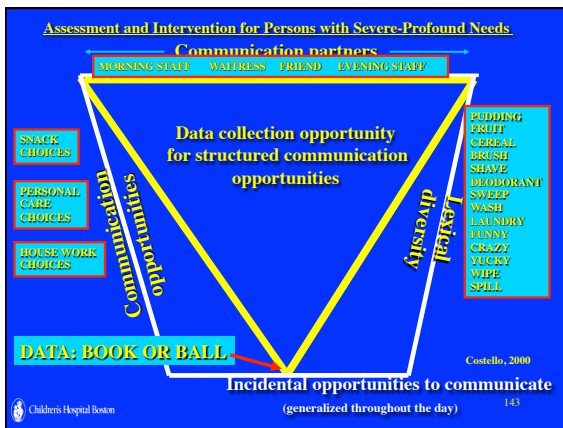
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You can be functional and scientific at the same time

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities





Age Appropriate or
Person Appropriate?


Our job is not to change a person's personality, it is to support the expression of that personality.

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

The business of being politically correct requires constantly shifting loyalties. For example, the concept of age appropriate has an interesting history. We need to remember that this term began as an injunction upon people providing services but has gradually become a burden to be borne by the people with different abilities themselves. At first, in response to the misconception that people with learning disabilities were eternally children, people were reminded that their respectful friends regarded them as being their actual chronological age. This meant that for someone's 25th birthday - even if the person had been assessed as having a 'mental age' of 2 - one wouldn't presume to buy a plush toy. This has subsequently become a prohibition for the person, however. So an adult who likes trains or dolls is not "allowed" to have them. What began as a way of saying "Let's make sure we don't insult a group of people who have been insulted enough" has become a practice that says: "Don't do what you want or be who you are. It embarrasses us."

- Herbert Lovett
Learning to Listen, 1996 145



Respecting a person for who they are and who they may become given the benefit of increased life experiences, opportunities and expectations

(Our Lives Teach Us Who We Are)

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So, what if someone doesn't want to 'choose' something that is age appropriate?

some people have had limited exposure to age appropriate options and need repeated and diverse exposure to develop interest in age appropriate items.

In the meantime...

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Principle of today and tomorrow
(Beukelman and Mirenda 05)

- Decisions for today meet immediate communication needs and match current capabilities and constraints
- Also concurrently expose individual to variety of age appropriate options to be incorporated into future repertoire.

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Non-Negotiable Supports

- **Communication Profile**
- **Choices**
- **Engineering for Participation**
- **Incidental Communication and Social Connectedness**
- **Providing Information through Multimodal strategies**
- **Support use of communication strategies and technology**
- **Support Effortless Success in the Community**

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Non-negotiable Strategy:


Developing a communication profile

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

How do we know how to support and recognize an individual's personality?


COMMUNICATION PROFILE



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The LANGUAGE OF EYES




Nonverbal Communication

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Respecting the People Who Know Best!

Patient video or photo



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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Communication may be many things including:

cry/whimper	push/pull
smile/laugh	reach/grab
scream/yell	hug/kiss
grunt/groan	pleasure sounds
tantrum	differential vocalizations
interpretation of affect	perseverative rituals
eye contact/staring	self injurious behavior
gaze aversion	delayed echolalia
gesturing/pointing	sign approximations
interpretation of behavior	respiratory patterns
and body movement	interpretation of physiological reactions
physical proximity	inventive gestures
touch body	use of symbols
interact with objects	

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INVENTORY OF POTENTIAL COMMUNICATIVE ACTS BY SIGAFOOS, AND WOODYATT

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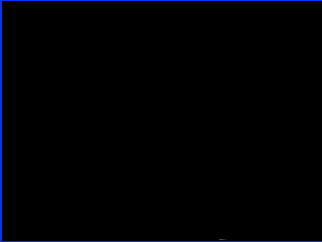
IPCA: Examples of Potential Communicative Acts

Vocalization	Body movement	Face/eye movement	Breathing	Challenging behavior	Stereotypic movements	Symbolic forms
Sounds	Moves closer	Purses lips	Rapid	Aggression	Arm flapping	Speech
Yells	Moves away	Stares	Slow	Tantrum	Hand wringing	Manual signs
Grunt	Tenses	Opens eyes	Hold	Self-injury		Gestures
Cry/whine	Wiggles	Closes eyes	Swallow	Destruction of items	Body rocking	Head nod
Laugh	Repositions body	Shifts eye	Sigh		Head weaving	Eye point
	Reaches/touches	Gazes away	Blow			Picture board
	Pushes/pulls	Gazes toward				
	Points					

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Communication Profile: The Introduction



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Requesting Activity

- desires attention
- desires significant person
- requests object
- requests activity
- requests food
- desires/initiates social interaction
- desires/initiates play
- requests assistance/help
- indicates does not want assistance
- expresses desire to engage in activity
- requests more
- desires affection
- desires information

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Examples of requesting activity

• <u>Desires attention</u>	• <u>Requests object</u>
✓ will stare at person	✓ will grab object
✓ will hit another person	✓ will stare at object
✓ will hyperventilate	✓ change in breathing
✓ will change physical proximity	✓ spits
✓ feigns crying	✓ yells/loud vocal
✓ reaches out hand toward others	✓ throws all objects but the desired one

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Negation

- Protesting
- Refusal
- Desires cessation of activity
- express negation/ rejection of object or person
- avoidance of person or request to do something

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Examples of Negation:

- Protesting
 - ✓ will yell
 - ✓ will stare you down
 - ✓ hit others
 - ✓ hit self
 - ✓ walk away
 - ✓ change in body posture
- Negation/rejection of object or person
 - ✓ hit
 - ✓ scratch
 - ✓ ignore
 - ✓ change in body posture
 - ✓ change in breathing

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Declaration/Comment


- Greetings
- Partings
- affirmations
- comment about events or actions in the past present or future
- about objects/person
- about error/mistake
- humor
- acknowledges information presented
- exclamation of emotional reaction

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Examples of Declaration/ Comment:

<ul style="list-style-type: none"> • <u>Greetings</u> ✓ spits ✓ yells ✓ eye contact ✓ fleeting eye contact ✓ will walk over to you ✓ will jump/yell/run away 	<ul style="list-style-type: none"> • <u>Humor:</u> ✓ laughs at loud noises ✓ laughs when others yell or get hurt ✓ repeatedly knocks things off tray/table ✓ puts items down his shirt and then looks at you
---	---

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Expression of Affect

<ul style="list-style-type: none"> • happy/pleasure • sad • angry • afraid/nervous • frustration 	<ul style="list-style-type: none"> • confusion • boredom • hurt feelings • exited • interested
---	---

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Examples of Expression of Affect:

<ul style="list-style-type: none"> • <u>Angry:</u> ✓ yell ✓ cry ✓ throw items ✓ self abusive ✓ abusive to others ✓ become silent ✓ will target a housemate 	<ul style="list-style-type: none"> • <u>Boredom:</u> ✓ throws objects ✓ target behavior against another person ✓ yells ✓ sleeps ✓ paces ✓ "gets into mischief"
--	---

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Examples of Expression of Basic Needs:

<ul style="list-style-type: none">• Hot:<ul style="list-style-type: none">✓ becomes flush in color✓ nothing - does not demonstrate, therefore, we have to closely monitor her✓ will have a seizure✓ will try to pull clothes off	<ul style="list-style-type: none">• Fatigue:<ul style="list-style-type: none">✓ very quiet✓ puts head down✓ will not stand up✓ will pull knees up to her shoulders✓ very whiney✓ fall to sleep
--	--

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Expression of Basic Needs

<ul style="list-style-type: none">• hunger• thirst• toileting (needs to, is currently, is soiled)• hot• cold	<ul style="list-style-type: none">• fatigue• sick• uncomfortable• pain• itchy
--	---

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Patient video or photo

Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Motivation . . .

- the desires, needs and interests that arouse (activate) an organism
- and
- direct it toward a specific goal

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Motivation to Communicate and Engage

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My Motivations:

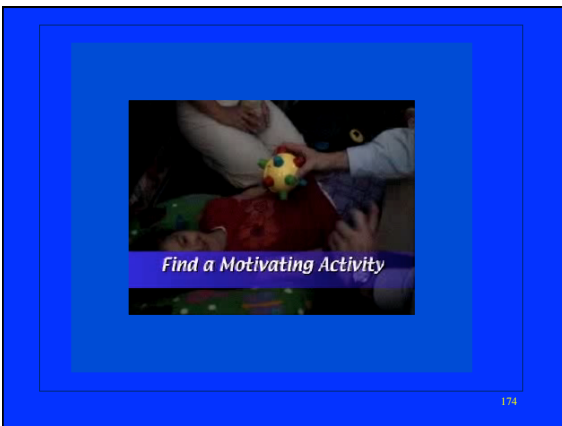


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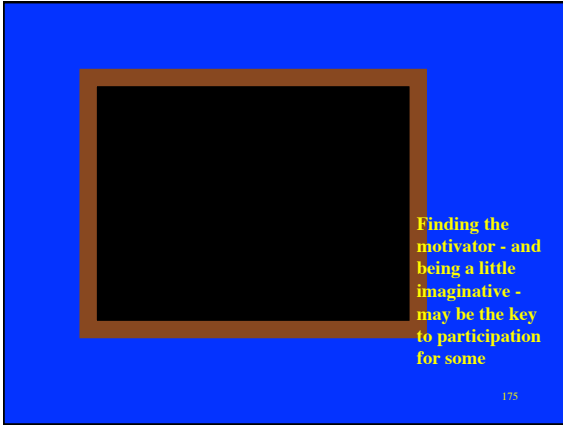
**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**





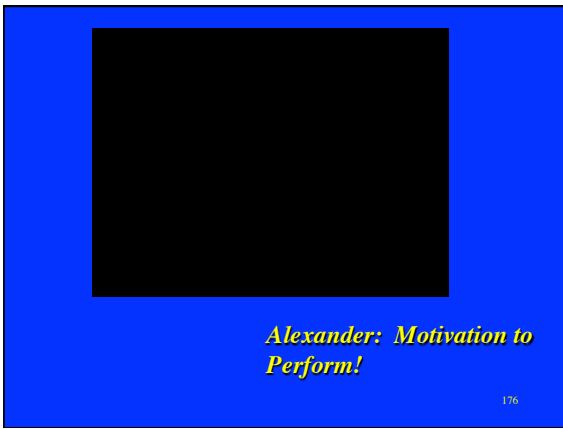


**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**



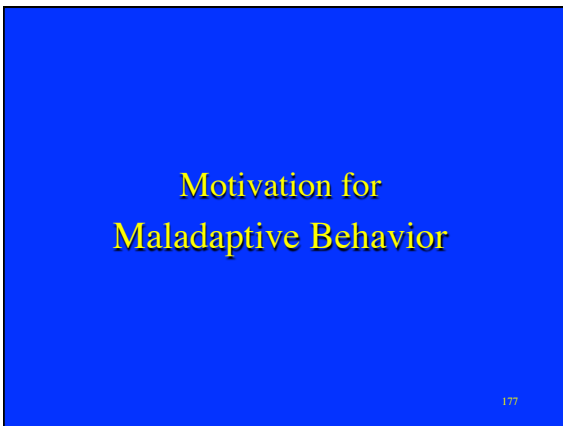
Finding the
motivator - and
being a little
imaginative -
may be the key
to participation
for some

175



*Alexander: Motivation to
Perform!*

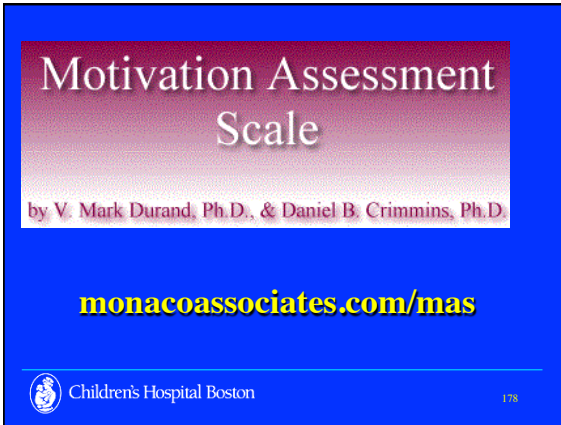
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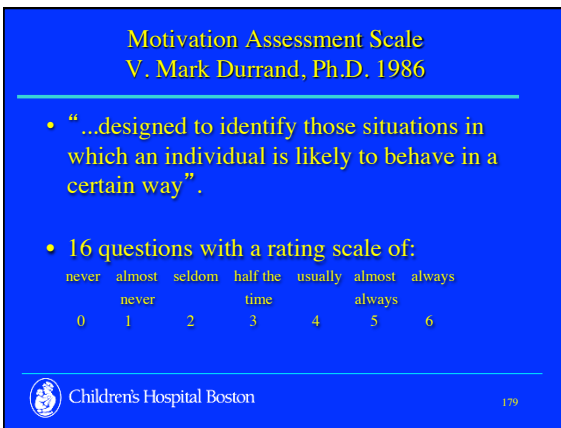
Motivation for
Maladaptive Behavior

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities



Motivation Assessment Scale
 by V. Mark Durand, Ph.D., & Daniel B. Crimmins, Ph.D.
monacoassociates.com/mas
 Children's Hospital Boston 178

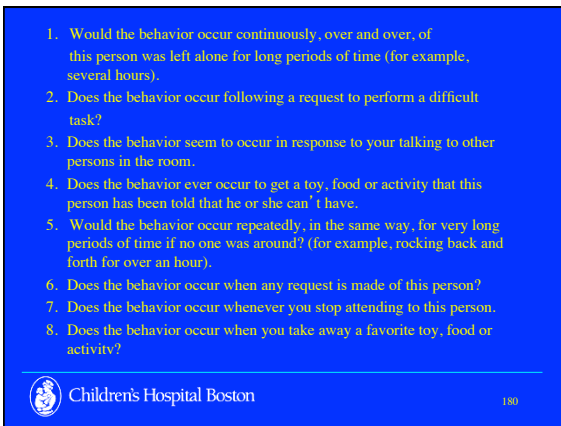


Motivation Assessment Scale
 V. Mark Durand, Ph.D. 1986

- “...designed to identify those situations in which an individual is likely to behave in a certain way”.
- 16 questions with a rating scale of:

never	almost	seldom	half the	usually	almost	always
	never		time		always	
0	1	2	3	4	5	6

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1. Would the behavior occur continuously, over and over, of this person was left alone for long periods of time (for example, several hours).
2. Does the behavior occur following a request to perform a difficult task?
3. Does the behavior seem to occur in response to your talking to other persons in the room.
4. Does the behavior ever occur to get a toy, food or activity that this person has been told that he or she can't have.
5. Would the behavior occur repeatedly, in the same way, for very long periods of time if no one was around? (for example, rocking back and forth for over an hour).
6. Does the behavior occur when any request is made of this person?
7. Does the behavior occur whenever you stop attending to this person.
8. Does the behavior occur when you take away a favorite toy, food or activity?

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

9. Does it appear to you that this person enjoys performing the behavior (It feels, tastes, looks, smells, and/or sounds pleasing).

10. Does this person seem to do the behavior to upset or annoy you when you are trying to get him or her to do what you ask?

11. Does this person seem to do the behavior to upset or annoy you when you are not paying attention to him or her? (for example, if you are sitting in a separate room, interacting with another person).


12. Does the behavior stop occurring shortly after you give the person the toy, food, or activity he or she has requested?

13. When the behavior is occurring, does this person seem calm and unaware of anything else going on around him or her?

14. Does the behavior stop occurring shortly after (one to five minutes) you stop working or making demands on this person?


15. Does this person seem to do the behavior to get you to spend more time with him or her?

16. Does the behavior seem to occur when this person has been told that s/he can't do something s/he wanted to do?

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Motivation Assessment Scale

- Sensory 1,5,9,13
- Escape 2,6,10,14
- Attention 3,7,11,15
- Tangible 4,8,12,16

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Exercise - two items


Volunteers???

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**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**

**Nonnegotiable Strategy:
Must Offer Choice**

**(not to be confused with
“Must make choice”)**



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Consider:

- Scenario:
- I've got two objects from which you are to choose.
- What does the instructor do/say?

Wh- question acquisition:

Question form	Age acquired	concept
Yes/no	2.0	
What + be	2.0	identify
What + do	2.6	action
where	2.6	location
why	3.0	Cause/effect
How (many, soon, big, etc.)	3.6 - 5.6 (size)	Manner/description
When	5.6	time
Which	5.6	selection

Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

ALWAYS offer options/choices throughout the day in all environments

Photos

Objects symbols

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MAKING CHOICES: A FOUNDATION OF INDEPENDENCE AND CONTROL

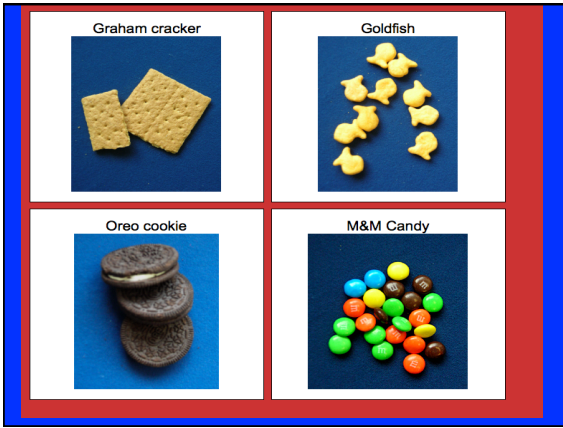
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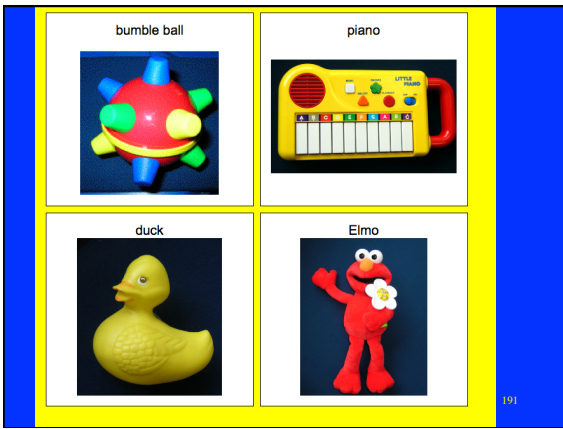
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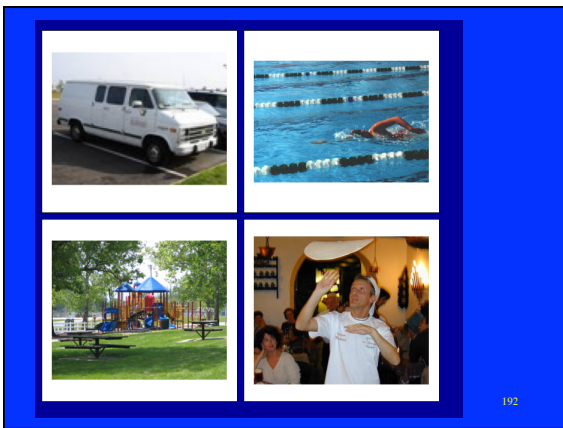
Light box with 'choices'

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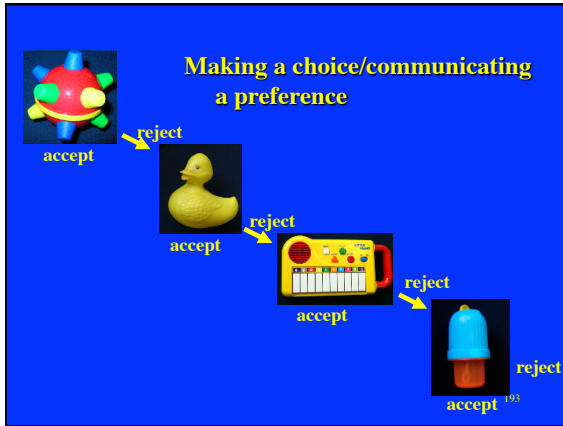
Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

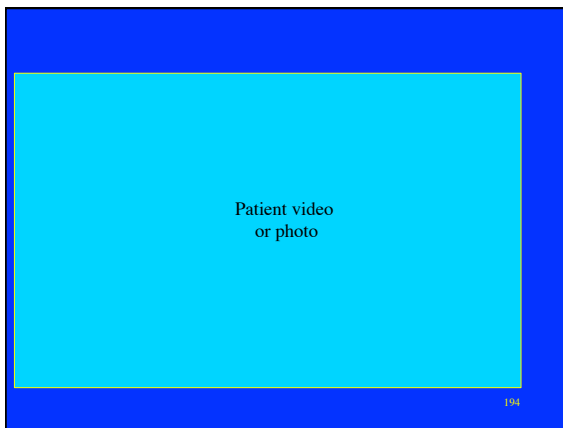






Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities





**Communication support
Does not equal technology:
Don't get caught up in the glitz!**

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

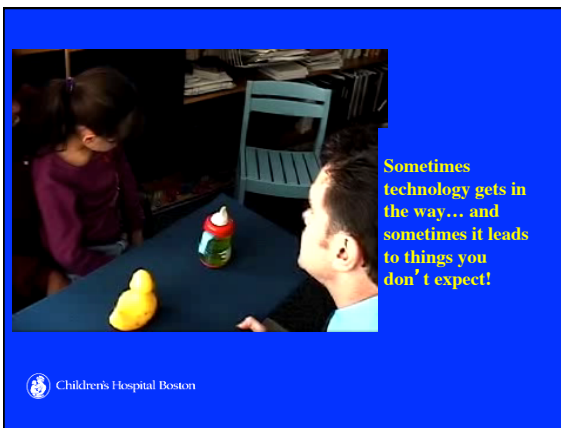






Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities





If you are offering choices...

How Do You Represent Meaning?

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Representations (not an absolute hierarchy!)

- Objects
- Object to object
- Reduced dimensionality
- Two dimensional
- Photographs
- Line drawings
- Symbols
- Standard orthography (sight words)
- Standard orthography (encode/decode)
- Linguistic acceleration techniques
- Morse code
- Auditory systems
- Tactile systems


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TANGIBLE SYMBOLS



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Charly Rowland, Ph.D.
Philip Schweigert, M.Ed.

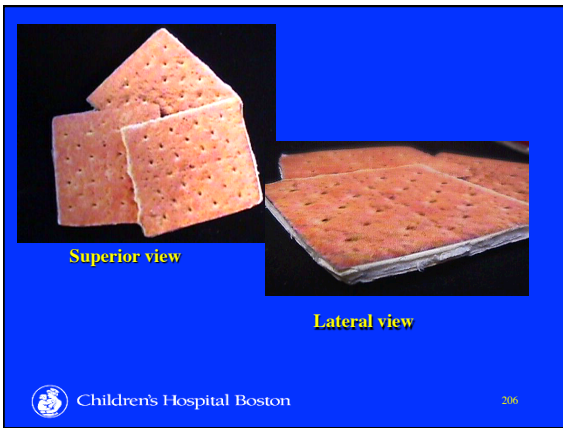
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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities









Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Ann Warrick Perception of Representations
Hugh MacMillan Ctr, Toronto, Canada


Awareness	(that there is something present)
Discrimination	(that it is a discreet form)
Recognition	(that it resembles something)
Comprehension	(that it has general meaning)
Attention	(that its meaning can be personally useful)
Memory	(that the representation can be used over and over again for personal use)

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How do we support a person to learn to “make choices”?
discussion!


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What if a person does not want to make a choice?

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Who makes the rules anyway?



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Who makes the rules anyway? -

- Throws items to eliminate the undesired choices
- Chooses each one and leaves desired item
- Will look at/stare at desired choice
- Will make choice only when sitting down
- Is dependent on a specific cue and does not respond to similar or related (e.g., "touch what you want" versus: show me what you want, point to what you want, what do

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Patient video or photo

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**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**

PATRICK

DOES HE UNDERSTAND?

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Non-negotiable:

**Engineering for
Independence and
Participation**

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or photo

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Some will need time and support to make the cause-effect connection

Break down the task in to steps

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Learning to have control: A

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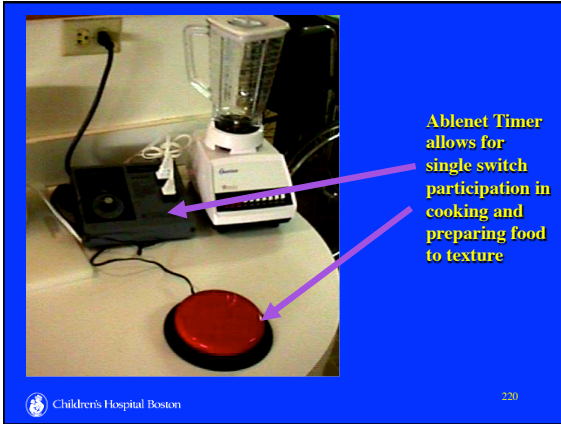
Engineering for participation

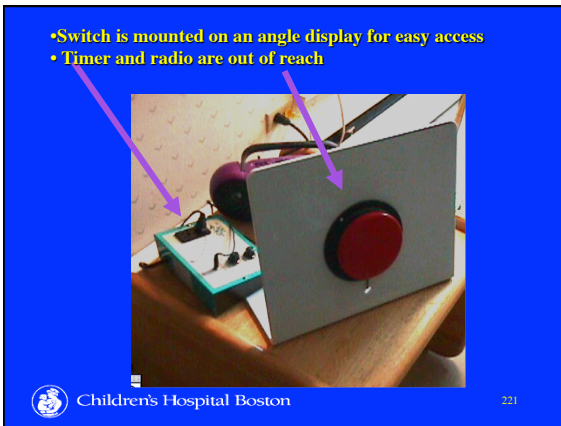
Can use single switch/dual switches and timers with:

- Tape recorder
- Food processor
- Spin art
- Radio
- Hair dryer
- Fan
- Light bright
- Vibrating pillow
- Vacuum
- Stereo
- CD player***
- Light box

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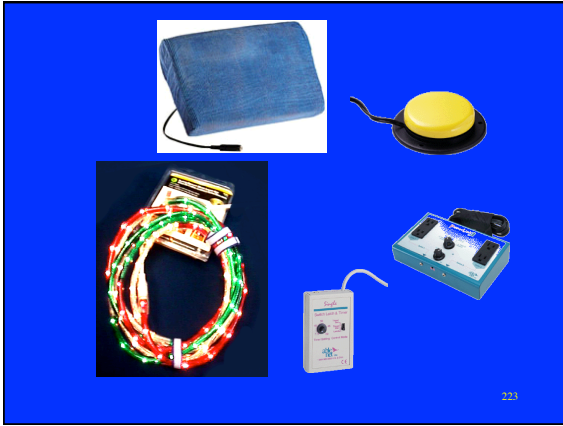
Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

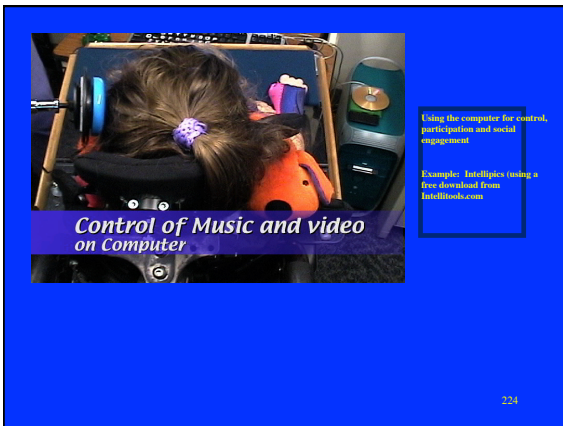


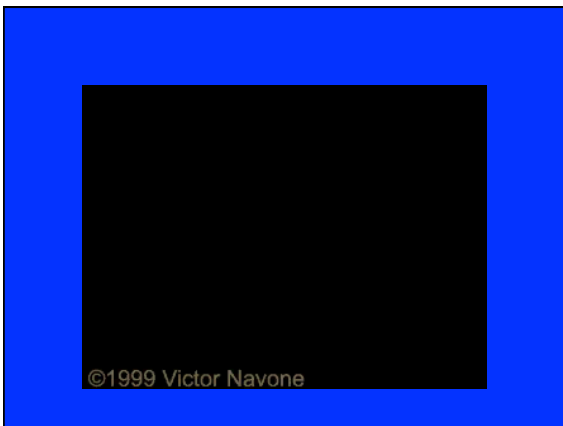




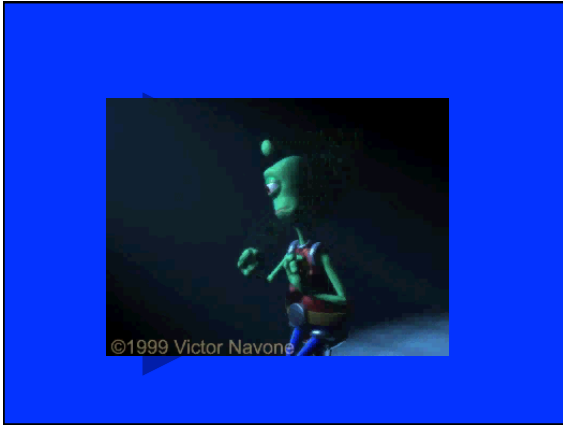
Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

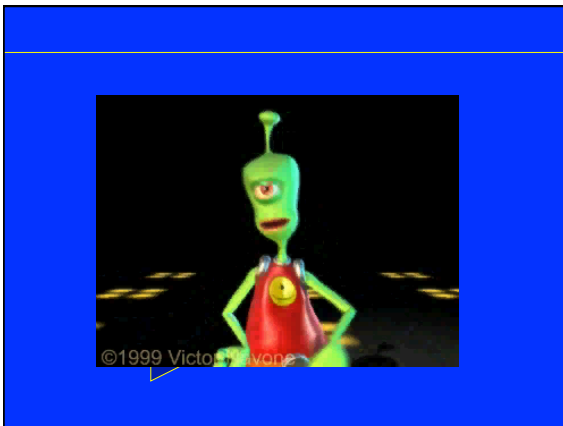


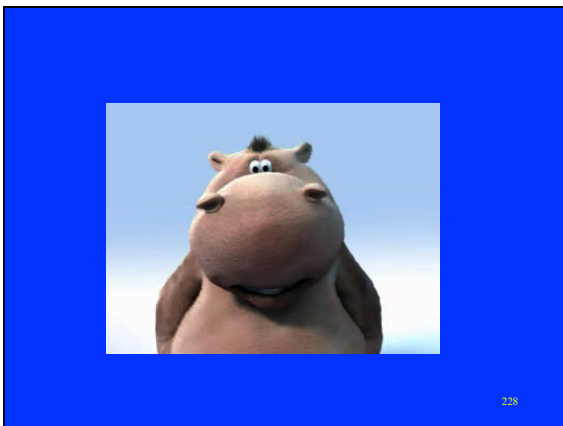




**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**







**Non-Negotiable Strategies to Support
Persons with Significant Developmental
Disabilities**

Computer for control
Switch It Maker or ppt

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Non-negotiable:
Incidental
Communication and
Social Connectedness

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**Incidental communication and
Social connectedness**


**Support incidental
communication and
Social connectedness throughout
the day using simple technology**

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

- **SINGLE MESSAGE SWITCHES**
- **DUAL SWITCHES**
- **SINGLE SWITCHES WITH MULTIPLE MESSAGES**

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Exercise with Step by Step:

Program 'something' that will encourage the Communication partner to participate for at least **THREE** turns.

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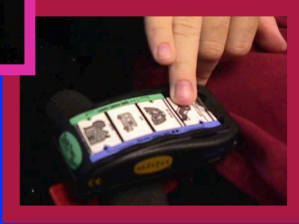


Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Ready access to speech output to gain attention and to learn increased Independence



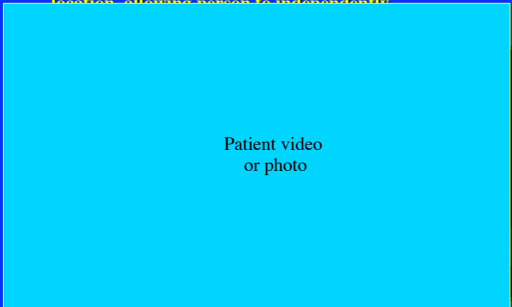
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General social statements For errorless success



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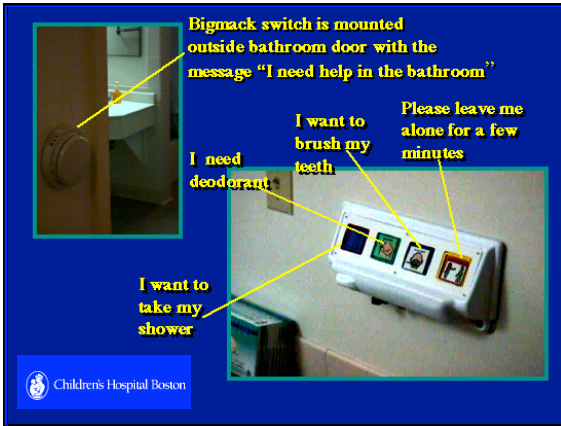
Step by step switch is mounted in a consistent location, allowing person to independently

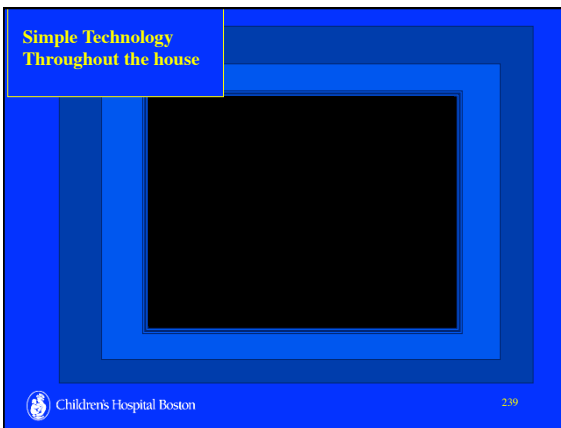


Patient video or photo

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities








Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Patient video
or photo

ping
white, P.D.
M., Ed.D.



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Group Activity:
Step by Step used throughout the day

Selected messages:

-
-
-
-
-
-
-
-

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Describe Ben's story

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

**Non-Negotiable:
Provide Information
Through Multimodal
Strategies**



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**Support people to be informed
about the activities of their day**




Photo calendar of staff schedule

Transition symbols for daily activities as an added receptive task (objects, object representations, photos, symbols)



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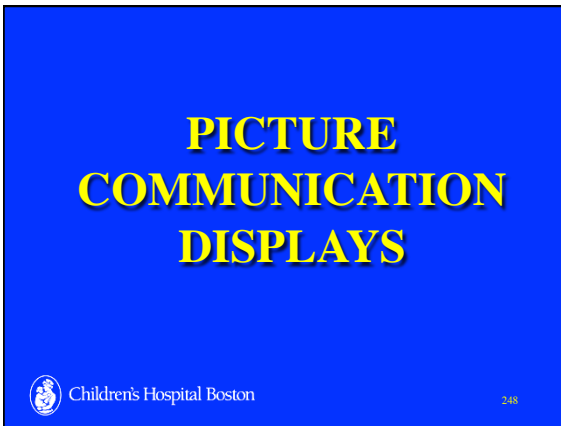
**OBJECT CALENDAR/
SCHEDULE SYSTEM**

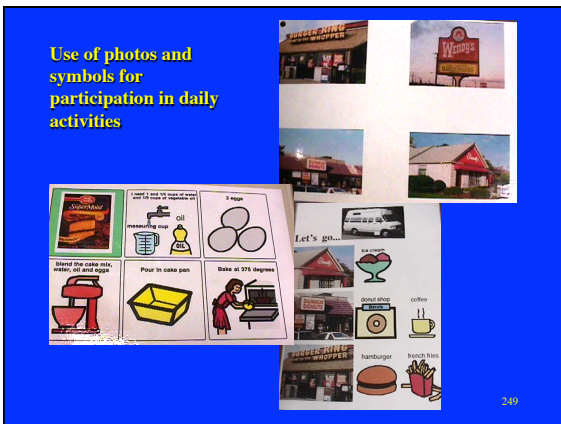


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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities



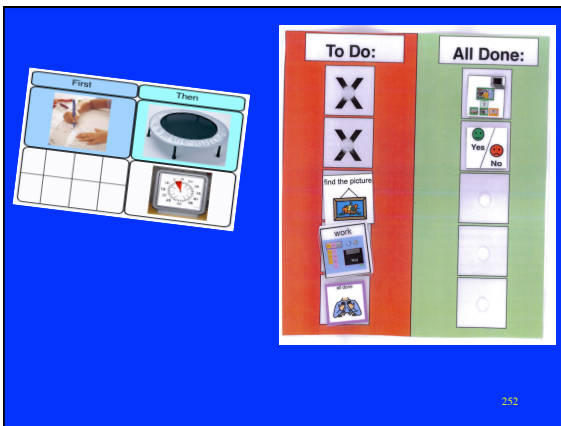




Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities







Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

First bath Then book

Washed Washed Washed Washed

Look at board Get Badge Watch tv Go to Cafeteria

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Jenny Abramson, SLP

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Creating a Grocery List

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities







Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

From Schepis and Reid, AAC V 19, 1 2003
Issues Affecting Staff Enhancement of Speech Generating Device Use Among People with Severe Cognitive Disabilities
Regarding staff training:

1. Understand how to operate and maintain devices
2. Understand the need for proper positioning
3. Understand the various applications
4. Ensure that individuals who use the devices have access to relevant vocabulary
5. Know how to identify and create opportunities for communication between individuals who use speech output
6. Are able to apply, as needed, behavioral teaching strategies designed to teach individuals how to use device
7. Understand how and when to prompt and respond appropriately to individuals

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Non-Negotiable:
**Support Effortless Success
in the Community**



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Support effortless success in the community by allowing people to be successful with communication AND be assumed to be competent communicators by people in the community.




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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Potential community messages for the One Step Switch

- Hi, it's nice to see you.
- Hi, how are you?
- Have a good day.
- I would like a large coffee please.
- I'd like to check out this book today.
- Thank you
- Happy holiday
- I take a size 9 bowling shoe.
- May I have a receipt
- Could you put the groceries in plastic bags please
- Where would I find _____.
- I need to buy _____
- May I have two adult tickets to 'Crocodile Dundee'
- Welcome to church!
- The registration line is down the hall and to the left.
- Please grind my meal before you bring it to the table.

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Ongoing Support and Study:

Simple AAC Technology to Support Community Inclusion For Persons with Significant Disabilities

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GOAL:


Effortless success with Communication when Outside home/work

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

Review of model:
Use of Simple Technology to Support Effortless Success With Communication in the Community

- technology
- Potential Messages
- Protocol
- Results

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Technology:
Criteria: Easy to use and requires no problem solving or decision making

Tools Used:

- Big Mack switch (AbleNet, Inc.)
- One Step Switch (AbleNet, Inc.)
- Voice Recording Picture Frame (Radio Shack)




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Must elicit response of some sort from communication partner

Sample Messages


- May I borrow this book please?
- I need a receipt?
- Could I have two adult tickets?
- Hi, how are you?
- I'd like the sunshine breakfast #2 and black coffee
- Hi, my name is Deb and I would like a perm

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities


Protocol for Use of Simple Technology in the Community

- Message is stored while still at home
- Recorded voice is age and gender appropriate
- Person recording should NOT be person accompanying/supporting in the community
- Same voice is used every time
- Message is spoken clearly, deliberately and politely
- Consistent and predictable community participation occurs (same place/same day/same time of day)

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Data collected

- **Date**
- **Name of accompanying person**
- **Where went**
- **Message spoken**
- **Specific response of person(s) in community**

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Obstacles to success:


- **Environment specific**
- **Staff specific**
- **Consumer/user specific**
- **Technology specific**

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

History of a Success Story:

- Initial visit - engage staff only (How did she do that? What did that say?, Does she know what it means?)
- 4 - 5 visits later - expectation!
- In some instances, staff have been chastised by people in the community for forgetting the technology




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Things we've learned:

- May need to turn device off immediately prior to functional use.
- One people in the community expect competence, they most often expect more
- Creating an audio tape of target messages may be most functional if don't have Step by Step.



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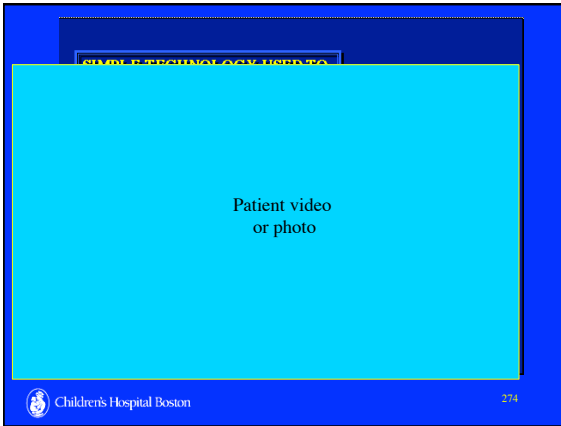
Patient video or photo

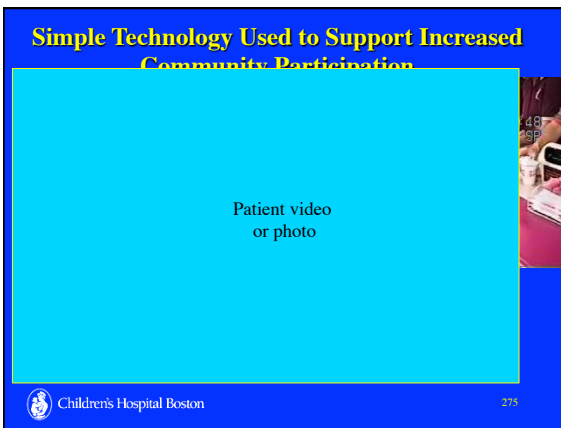


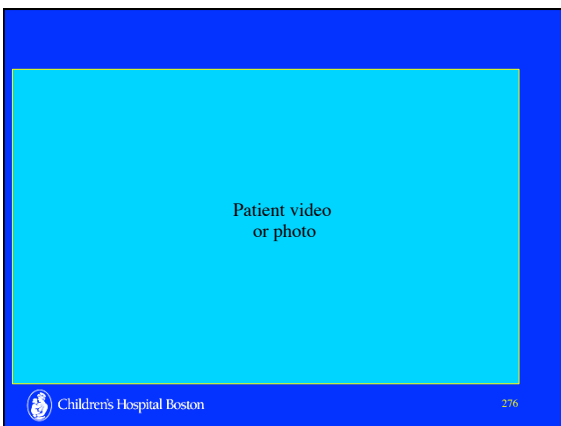
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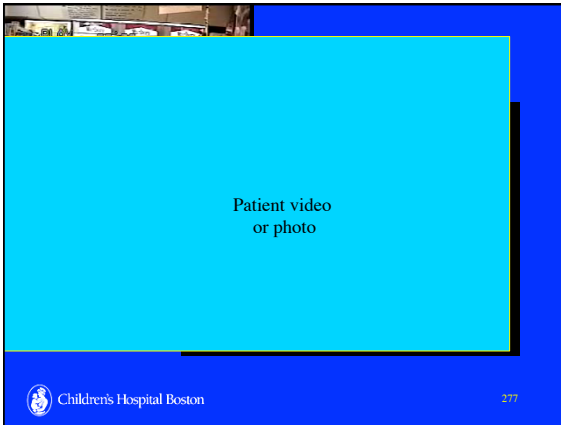
Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities





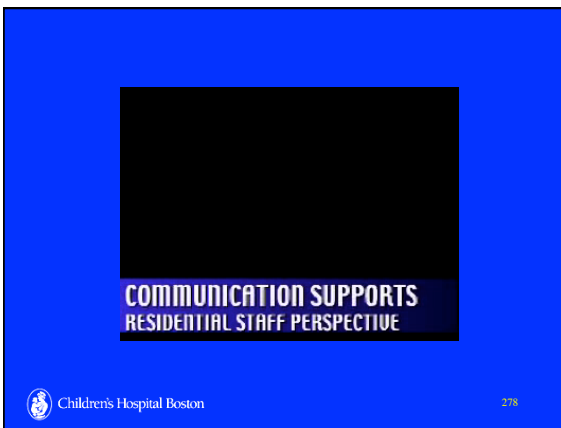


Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities



Patient video
or photo

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COMMUNICATION SUPPORTS
RESIDENTIAL STAFF PERSPECTIVE

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Benefits of Encouraging Communication Through Augmentative Means for Persons with Complex Needs:

- Incidental learning opportunity
- Promote increased social contact
- Increased context for interpreting vocalizations
- Increased opportunity to integrate into society
- Educate people in the community

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Non-Negotiable Strategies to Support Persons with Significant Developmental Disabilities

When is enough enough?

Answer: Communication can always be supported.

Philosophy: Expect it, don't require it

translation: One must always have communication opportunities available, always being allowed to be independent first and provided with support second.

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Developing Meaningful Communication Goals

Audience case presentation:

Goal development

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