

What does it take to be a leader in promoting the use of Augmentative and Alternative Communication?

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Christopher Hitchens, "Unspoken Truths" Vanity Fair, June 2011

Like health itself, the loss of such a thing (loss of voice) can't be imagined until it occurs. In common with everybody else, I have played versions of the youthful "Which would you rather?" game, in which most usually it's debated whether blindness or deafness would be the most oppressive. But I don't ever recall speculating much about being struck dumb.



What do we do to communicate?

Sending messages

How?



Talking...







Using gestures



Pointing, facial expressions



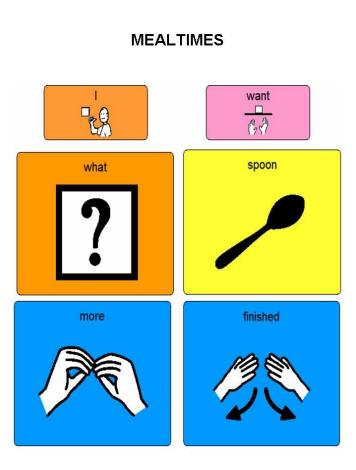


- Identify objects
- Make physical contact



Communication boards and AAC devices







What is

Communication really About?

..listening





- Observing
- Seeing
- Understanding





It's about sharing..

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Closeness, friendship

And the ability to make sense in interaction with others

MEANING – the ability to build relationships





MEANING – the ability to build relationships

- Being able to engage with others
- Positive relationships

Well-being

- Martin Seligman (2011):
 Flourish
- move from Authentic Happiness



MEANING – the ability to build relationships

What are the challenges in using AAC strategies?

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- Imposing a new system into natural interaction situation
- Difficulties in getting to use this system as it is atypical (intrusive)
- Complicated (demanding to use) – need to do it one step at a time
- We should to not be side tracked. Focus on engagement with others (needs to be internally rewarding – communication intent)
- Time-intensive



What do we know about using different strategies of communication (AAC)?

- It is much slower than speech
- Others don't always understand or know how to use the strategies to interact with people who use AAC
- People get impatient, rather walk away than talk to people who use AAC
- AAC users are dependent on others to assist them
- It is not only about teaching an individual skill, but the process of engagement



What types of leaders do we need to promote AAC?

The legacy of Nelson Mandela

- Tolerance
- For the good of all
- Forgiveness
- "That you fall is not that important – it is how you get up"
- 67 minute community service to celebrate Mandela's 93rd birthday



What does it mean to be a leader in promoting AAC?

Based on Johannesen, Valde & Whedbee (2008)

It means 4 things:

- Sensitivity: Know what is available and what could work - situational understanding
- 2. Moral Direction: what is fair?
- 3. Taking responsibility: Commitment & motivation to do something about it,
- 4. Energy to persist: character, backbone

If you have the first three and not the last – nothing will happen.

Sensitivity: Knowledge and Application in context

- Knowledge about :
 - AAC, different strategies available: low and high tech, manual signs
 - and its implementation
- Dedication to develop training courses in AAC to provide a scientific basis for implementation & skill to apply these within the context
- No one-fits-all recipe: individuals who use AAC and families have different needs and expectations

Moral Direction

Moral: Generally agreed-upon cultural standards

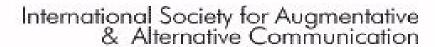
- Fairness and social conscience
- Stand up for what we believe in
- Tension between what "is" an what "ought to be"

Take responsibility

- Commitment & motivation to do something about it
- Take Initiative to engage those who should be involved
- Make sure that there is built-in accountability
 - Quality
 - Outcomes

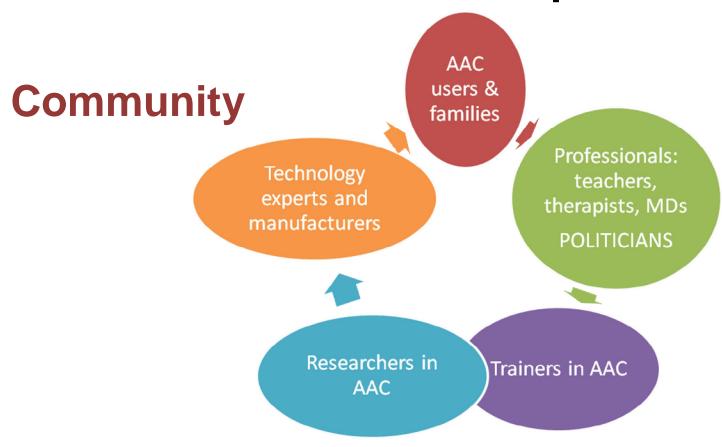
Energy to persist

- Character, backbone
- Being there through ups and downs
- Learning from mistakes: not to be discouraged
- The power of one...
- Being able to sustain energy: know how to protect your own energy and those of others..
 and live





Who should take leadership?



Ghost boy (Martin Pistorius, 2011)

- His realization: the box (p. 13 & 14)
- His Father: care and initial lack of communication
- His mother: fighting in the family. (p.62)
- Siblings: what about the other children?
- Friends Care centre
- Professionals how much we really can't do..
- Technology what it takes to program for communication
- What it takes to make friends...and to dream

Different types of leadership

- Traditional model of leadership:
 - How can we understand their suffering
 - How can we rehabilitate get them out of suffering
 - Deficit model
- New Leadership:
 - How can we understand what makes the individual and family flourish
 - How do we increase their ability to flourish and people and families in the community

What are we working for?

Strong leadership partnerships within communities that can promote the use of AAC

- A Voice for All
- Empowering families to support their own
- Proficient AAC users that can dream and be mentors for other young people
- Dedicated trainers, clinicians and researchers who support the efforts of AAC users and families
- Innovative AAC technology experts and manufacturers that can develop easy to use devices to facilitate interaction.
- Politicians that promote our cause

What does it require?

- Keeping our eye on the ball ...it is not about the latest technology – rather it's about communication and friendship and how technology can facilitate this process.
- Changed service provision models? Can present services and cost structures really provide what is needed? Do we really serve families?
- Leaders in promoting AAC are those who with humility and awareness are able to maintain what is good, but..
 - have the courage to work for change to ensure more relevant services to families and those who use AAC



How do we move forward?

- Sensitivity
- Moral direction
- Responsibility,
- Energy

Thank you Ke a le boga

See you at the ISAAC Conference in Pittsburgh, USA in August 2012

- be there!

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