



The USSAAC Webinar Series

May 8, 2019

7:00 PM Eastern

**Mental Health and Students with
Complex Communication Needs: Let's Talk About it!**

Presenter:

Kathy Howery, Ph.D.

Webinar Logistics



ASHA CEUs – live webcast

- Included for USSAAC members;
\$25 – non-USSAAC members
 - Participant form and instructions on USSAAC website
 - Can only receive CEUs for *live* webinar
 - **NOTE: You need to scan and send participant form to smeehan8@ku.edu by May 17, 2019**
- Archived webcasts
<https://www.isaac-online.org/english/news/webinars/>
 - Enter questions in the question pane. We will answer as time permits.



WHAT WILL YOU LEARN?

- How mental health can be negatively affected by communication challenges.
- About how the impact of having to make one's voice heard through a SGD may create situations of vulnerability and abuse for students in institutional context.
- How the Communication Bill of Rights (Brady et al, 2016) can be used to proactively address potential maltreatment and support mental wellness in children and youth who use AAC.

Supporters

USSAAC would like to recognize and thank our Institutional and Corporate Members for their support



Supporting people who use AAC and their families affected by disasters: <https://aacdisasterrelief.recovers.org/>

AAC Disaster Relief

Community Admin



This site supports individuals who use AAC so they can re-establish their communication. The United States Society for Augmentative Communication (USSAAC) manages the site and is currently focused on the aftermath of hurricane IRMA.

I Have A Need

Get assistance:
connect with the goods
and services you need.

I Want to Give

Send supplies:
connect with people
who need them.

I Want to Volunteer

Lend a hand:
connect with people
who need your help.

Locate or suggest donation centers, shelters, and other recovery resources:

 Find Resources »



Emergency Information

Emergency: 911

Edit Info

Post Documents



Update Slideshow

Community Updates

Post Updates

Welcome to AAC Disaster Relief for Hurricane Irma [Edit](#)

posted 1 day ago by CERV from [Community Emergency Response Volunteers of the Monterey Peninsula](#)

No comments yet • Labels: hurricane irma aac ussaac communication needs

This site assists people with severe speech and language disabilities who use augmentative and alternative communication (AAC) to enable them to communicate. We are focusing on the aftermath of Hurricane Irma. Help us get the word out!

Individuals who use AAC and their family members can request help or sign...

[Read More](#)



New Site added to address needs of people who use AAC and their family members impacted by Hurricane Irma [Edit](#)

SAVE THE DATE! June 4, 2019, 6:00 PM Eastern

Dave Banes and E.A. Draffan, Global Systems: Design and Use of Symbols that Reflect Local Language and Culture

Check back at <https://ussaac.org/news-events/webinars/> for additional details and registration information. Follow USSAAC on Facebook for up-to-date and “breaking” news.

Please consider joining USSAAC! Check out <https://ussaac.org/membership/> for benefits!

Mental Health and Students with Complex Communication Needs



Kathy Howery, PhD

May 8 2019



Did you know it's Mental Health
Week?

CMHA

Mental Health Week

#GetLoud

May 6-12, 2019



THINGS TO TALK ABOUT...

- Mental Health and why it matters.
- Stories from young people with CCN.
- Referring the Communication Bill of Rights (and other supports)
- Ideas support the mental health of students who require AAC

But first...



- Monica Braat, Inclusive Education Lead, Medicine Hat Catholic Schools ***
- Dr. Dick Sobsey, Professor Emeritus, Educational Psychology, University of Alberta
- Erin Sheldon, AT Specialist, AAC Specialists, Special Ed Lead for Assistiveware...
- Dr. Harold Johnson, Professor, Special Education, Michigan State University
- The participants in my study who entrusted me with their lived experience ***

People who have **complex communication needs** are unable to communicate effectively *using speech alone*.

They and their communication partners may benefit from using alternative and augmentative communication (AAC) methods, either temporarily or permanently. Hearing limitation is not the primary cause of complex communication need.

definition

Perry et al. 2004



Mental Health

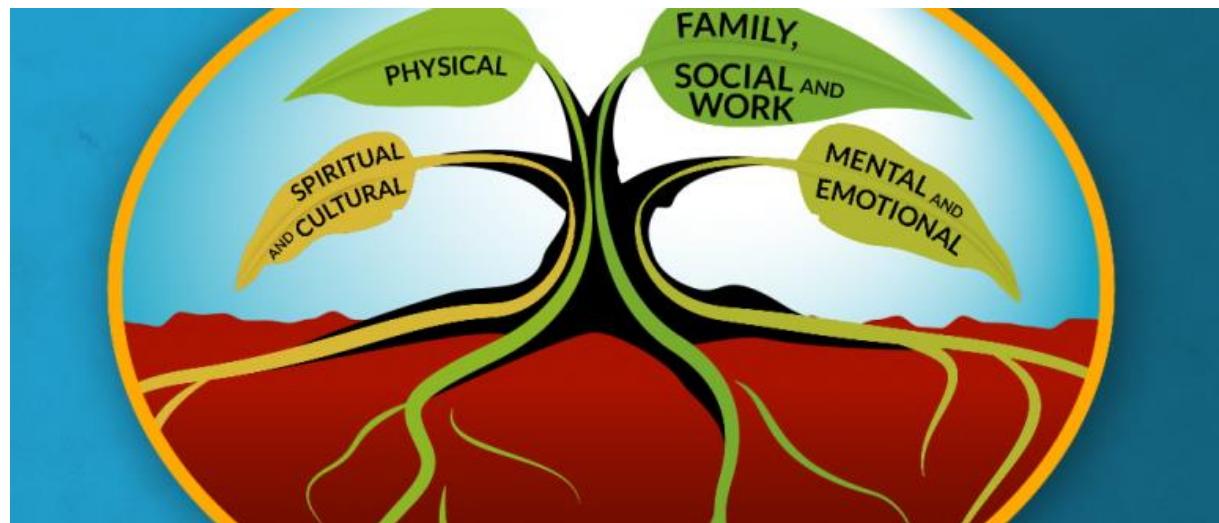
Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.



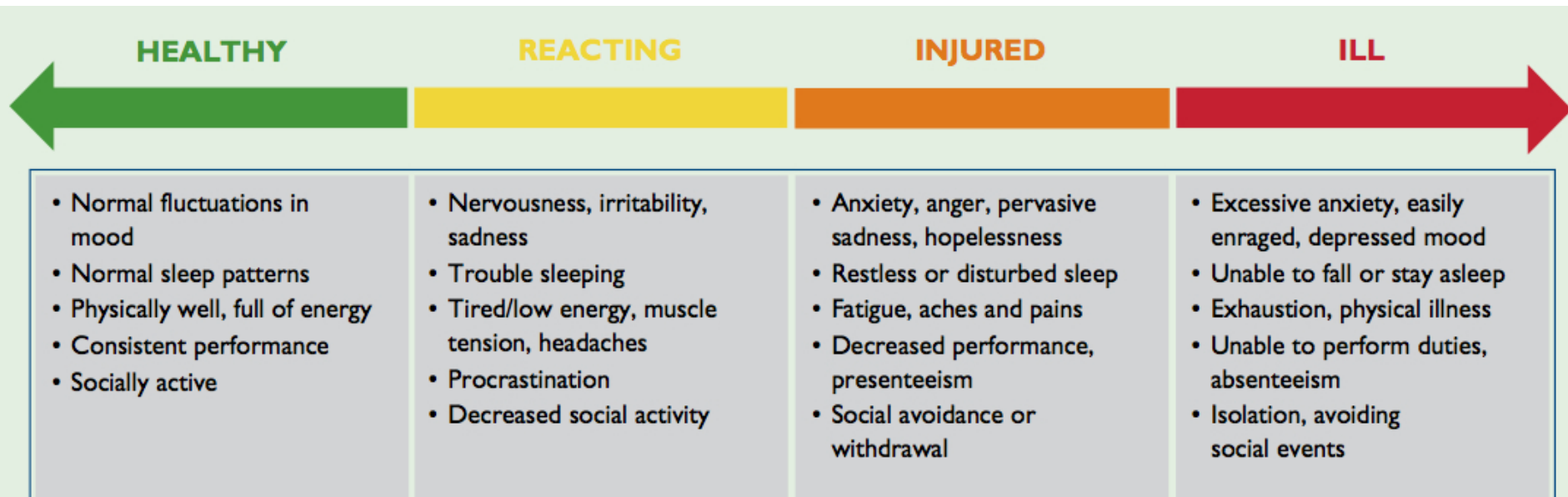
**World Health
Organization**

Mental Health

Mental health is not fixed. It is influenced by a range of factors, including life experiences, learning and work environments and the social and economic conditions that shape our life.



Mental Health Exists on a Continuum



Mental Health is



... the underpinning success and achievement for any student is the quality of their mental health

Carpenter, 2009

Health is the basis for a good quality of life and mental health is of overriding importance in this.

*UN Convention on the Rights of the Child,
Article 24*

Protective and Risk Factors that Affect Mental Health⁸

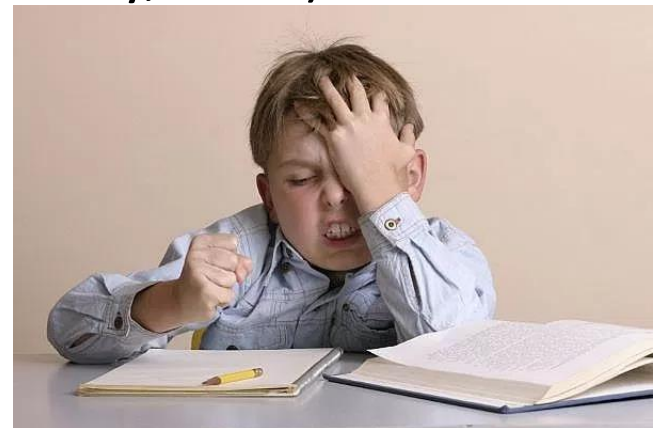
	Protective Factors are conditions or attributes that protect mental health	Risk Factors (or adverse factors) that may threaten mental health
Individual Attributes	<ul style="list-style-type: none"> • Positive sense of self, confidence • Ability to solve problems and manage stress or adversity • Communication skills • Physical health and fitness 	<ul style="list-style-type: none"> • Negative sense of self • Emotional immaturity and limited ability to manage stress and solve problems • Difficulties communicating • Chronic health condition or frequent illness • Substance abuse
Social Circumstances	<ul style="list-style-type: none"> • Social support of family and friends • Healthy family interactions • Physical and economic security • Scholastic achievement 	<ul style="list-style-type: none"> • Loneliness, bereavement • Neglect, family conflict • Exposure to violence or abuse • Low income and/or poverty
Environmental Factors	<ul style="list-style-type: none"> • Equality of access to basic services • Social justice and tolerance • Social and gender equality • Physical security and safety 	<ul style="list-style-type: none"> • Limited access to basic services • Injustice and discrimination • Social and gender inequality • Exposure to war or disaster



Language and Mental Health

45% of young people referred for mental health services have communication difficulties. (Cohen, Farnia, & Im-Bolter, 2013).

Language difficulties in students who access mental health services often go unidentified as the focus is on the **externalizing and internalizing behaviours**. (Bornstein, Hahn, & Suwalsky, 2014).



- Autism – Higher Prevalence of Anxiety, OCD, Depression
- Rhett Syndrome – Anxiety as a Characteristic
- One out of every two children with CP will meet the criteria for some form of psychiatric disorder, with attention deficit hyperactivity disorder (ADHD) being the most prevalent. The study indicated that around 40% to 50% of school-aged children with cerebral palsy exhibit emotional and behavioral problems. (*The Scientific World Journal* - Volume 2013, Article ID 468402)

A population at risk!

Children with disabilities are more likely to experience maltreatment & abuse than children without disabilities (Crowley, 2016; Jones et al., 2012).

*the odds of experiencing **reported abuse** are more than **three times higher** for a child with any type of disability...and **four times higher** for a child with intellectual or mental disability than for a child without a disability (Sobsey, 2017, 149).*

And what to do if you need AAC supports to talk about it?



Shared experience





National Joint Committee for the
Communication Needs of Persons
With Severe Disabilities (NJC)

COMMUNICATION BILL OF RIGHTS

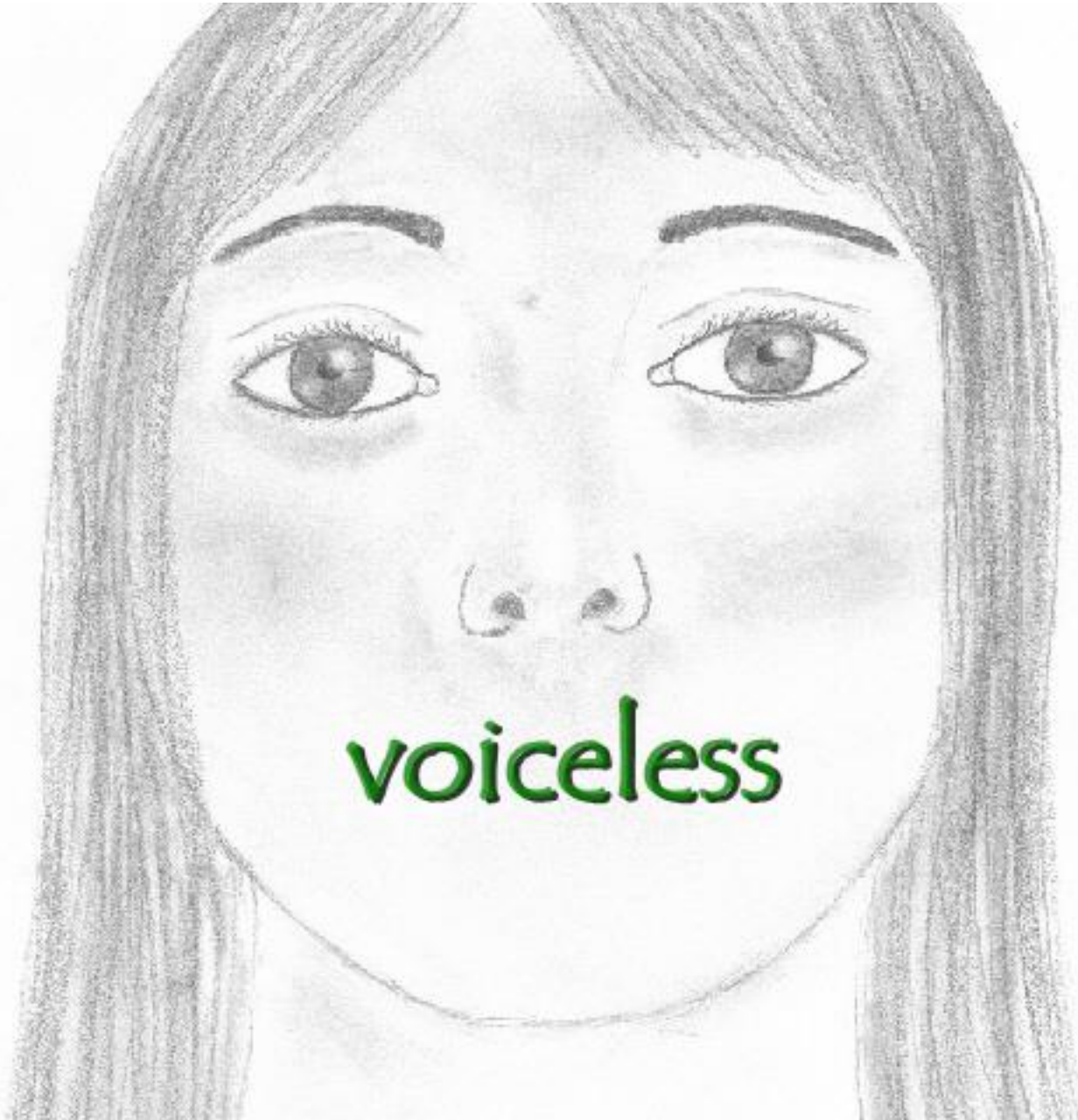
All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

1. The right to interact socially, maintain social closeness, and build relationships
2. The right to request desired objects, actions, events, and people
3. The right to refuse or reject undesired objects, actions, events, or choices
4. The right to express personal preferences and feelings
5. The right to make choices from meaningful alternatives
6. The right to make comments and share opinions
7. The right to ask for and give information, including information about changes in routine and environment
8. The right to be informed about people and events in one's life
9. The right to access interventions and supports that improve communication
10. The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
13. The right to be treated with dignity and addressed with respect and courtesy
14. The right to be addressed directly and not be spoken for or talked about in the third person while present
15. The right to have clear, meaningful, and culturally and linguistically appropriate communications

For more information, go to the NJC website at: www.asha.org/njc

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Prid, D., Romski, M., Sevcik, R., Siegel, E., Schoenow, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities, 121*(2), 121-138.

11220





"I go school in morning, my tray on my chair with my device. My aide put my device on wall shelf and take off my tray. I no use my device in classroom.

I no no why???"



Access to Communication

I can understand what he wants without the device

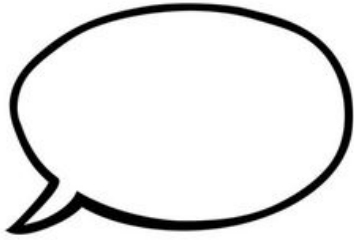
"She doesn't ever use it"

It's just easier without the device in the way

COMMUNICATION BILL OF RIGHTS

11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times





"My first class we started a group project. My teacher started numbering off people and dividing them into groups. I was nervous to work with new people that I didn't know but I knew I was going to kick ass at this project which was a skit, ordering your favourite food. After everyone had gotten into their groups, I asked which group I was in.

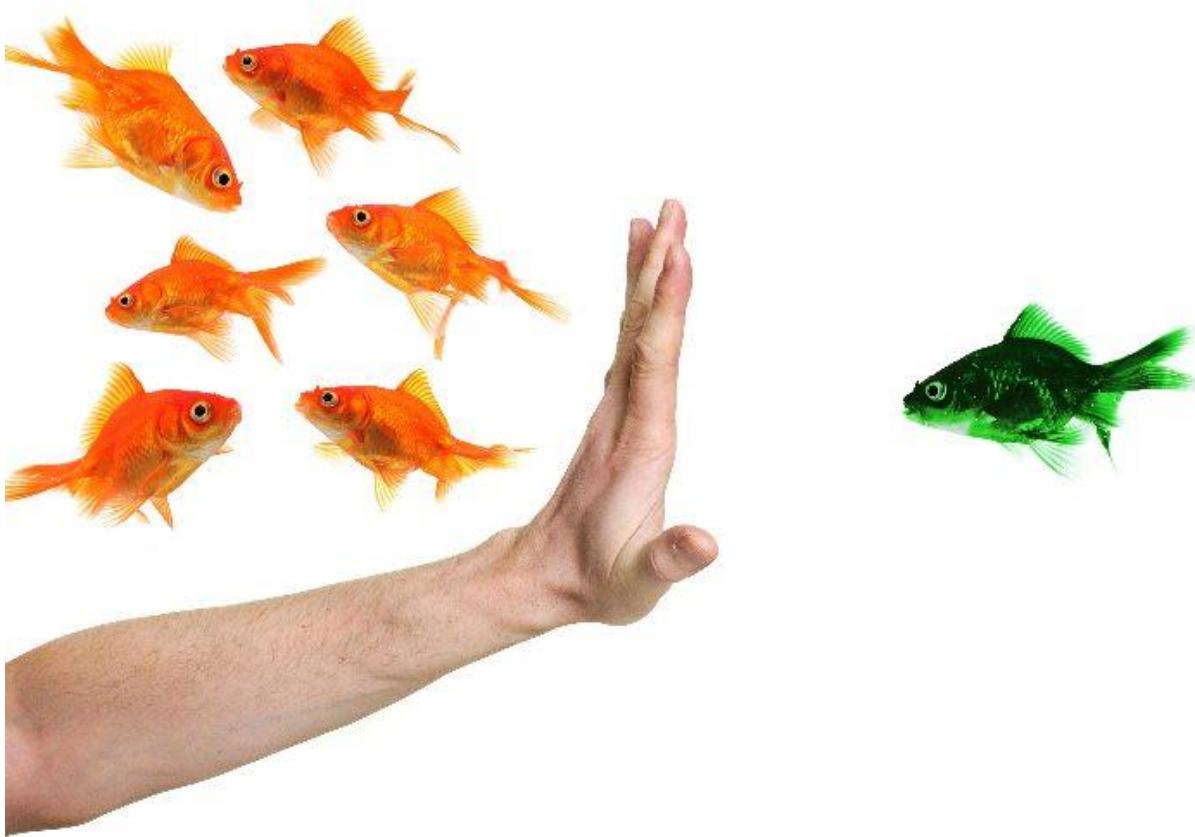


My teacher told me I was better off working by myself.

I was scared, livid and embarrassed. I immediately wanted to withdraw from the class. I had never been so boldly excluded."

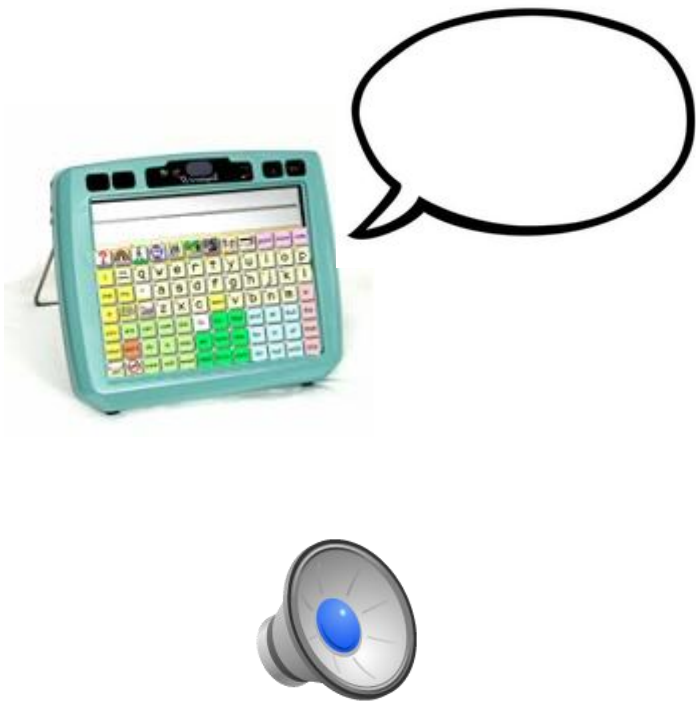


"Othering" and Isolating

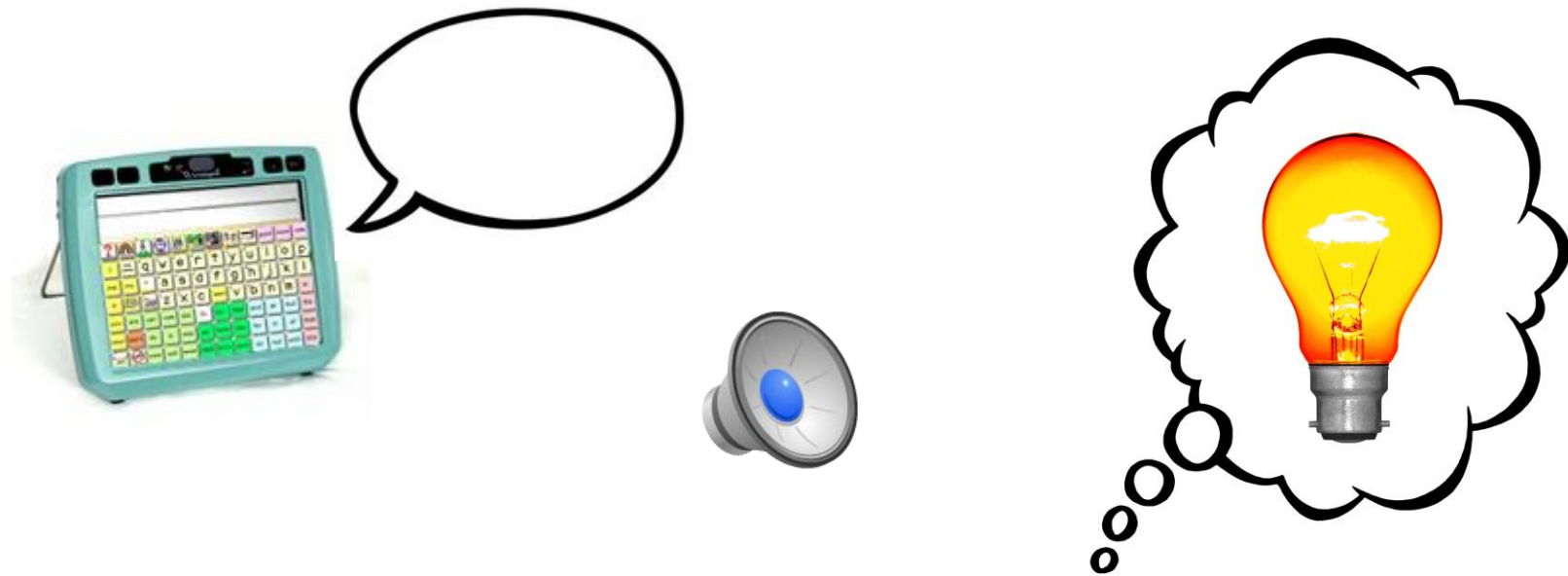


COMMUNICATION BILL OF RIGHTS

12. The right to access environmental contexts, interactions, and opportunities that promote **participation as full communication partners** with other people, including peers.



"I remember when I got my V. I was really excited and wanted to know where all the symbols were and how how to say things with it."



"I came up with a great idea. Every Friday my class went Roller Skating, everybody teachers, aides, kids, everybody. While this was fun for lots of the kids I roll around all day already so it wasn't a lot of fun for me. So I asked if I could stay back at school on Fridays to learn my device."



"At first the school said no everyone had to go but when my mom got mad they changed their minds. One of the teachers had to stay back with me. I was so happy, I thought I would have some real time to learn AND someone who I could talk to and practice with. But that is not how it went."





"The teacher was so mad at having to stay back at school instead of going to the roller rink that he didn't talk to me the whole time. I just sat exploring my device on my own and he sat marking papers or whatever at his desk.

So much for that great idea. I could have talked to myself at the roller rink."





Abuse of Power





Power and Control Wheel

Based on a wheel developed in Duluth, Minnesota, by formerly battered women to describe their experiences, **this wheel illustrates forms of abuse experienced by persons with developmental disabilities abused by their paid caregivers.** It offers a way to think more broadly about abuse than physical or sexual abuse only.

A. Coercion and Threat

B. Intimidation

C. **Caregiver Privilege**

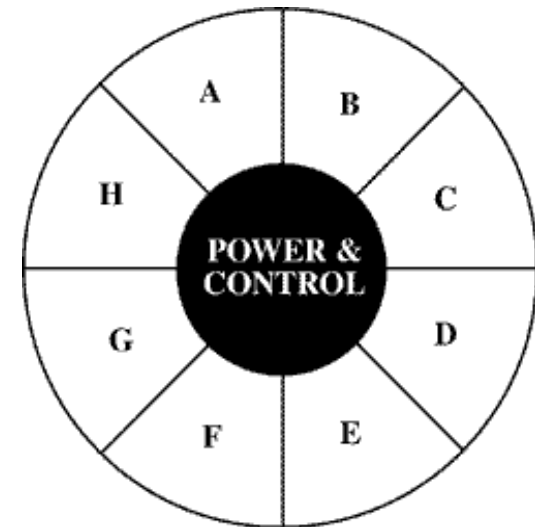
D. **Isolation**

E. Minimize, Justify and Blame

F. **Withhold, Misuse or Delay Needed Support**

G. Economic Abuse

H. **Emotional Abuse**



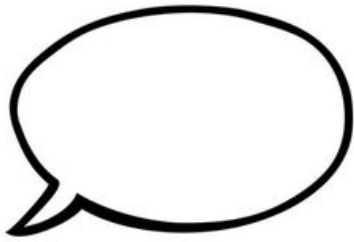
Source: <http://www.broadreachtraining.com/advocacy/artpowcon.html>

COMMUNICATION BILL OF RIGHTS

4. The right to express personal preferences and feelings.
9. The right to access interventions and supports that improve communication
13. The right to be treated with dignity and addressed with respect and courtesy.



"The year I turned ten was a really hard year for me."

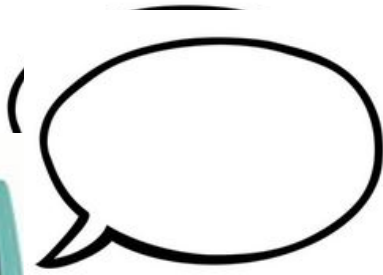


"Elementary school was pretty rough, although maybe I didn't know it at the time. How could I have, it was the only life I knew.

I was in the regular classroom during elementary school, and I had a teaching assistant. She did not want to be with the kid like me! Not a kid that drooled, and had to be taken to the bathroom, and had to be lifted, and had to be fed.

She sure wasn't interested in hearing what I have to say either through my communication board or through my device when I got it."





*"I remember when she took me to the bathroom she would tell me that I was fat and that I would be a burden to my mom and dad. Then in class she would tell me to quit drooling and **yell at me in front of all the other kids.***

*I just got to feel really bad about myself and mostly didn't take the risk to say anything. **Thinking back on it now I think she was the one that silenced me.**"*





'Safe' people may not be

It is important to recognize the reality that school staff are sometimes the abusers.

We need to teach our children that bullying is not just encountered by their peers. Sadly they may encounter bullying from adults as well.



someecards
user card



"I did all sorts of things to rebel, like not doing my work or slowing down my reading. Instead of asking me what was the problem, Mrs. W decided to teach me a lesson by bullying me.

She did this bullying in the bathroom where I couldn't fight back because I had no device there."





"She said I was fat and going to be a burden to my mom and dad when I grew up. She also said I smelled. I got so nervous going to the bathroom, I pooped my pants.

I endured this bullying for over two years."





Voiceless = Powerless



A survey of sexual abuse of students with disabilities in American schools reported that **school staff were responsible for about half the cases**, and students were responsible for the other half.

- Teaching staff – perpetrators in 30.3 % of cases
- Other school staff:
 - PTs/SLPs 8.3 %;
 - non-professional school staff 6.1%;
 - transportation providers 5.1%;
 - school administrators 21.1%

Caldas & Bensy, 2014 cited in Sobsey, 2017

“Wide Open Spaces”

... her safety would be found in wide open spaces with people who knew her well but had no power over her...

...she would be most vulnerable in separate settings with people who had power over her and no competent witnesses.

Sheldon, 2019, p.8

COMMUNICATION BILL OF RIGHTS

1. The right to interact socially, maintain social closeness, and build relationships

13. The right to be treated with dignity and addressed with respect and courtesy.

We need to teach our children that bullying is not just encountered by their peers. Sadly they may encounter bullying from adults as well.





"She also sent me out of the classroom for drooling, because she heard some other schools did it that way.

That year I got my first talking device, which was called a Touch Talker. My therapist came in to school to teach me Minspeak."





"I feel she did a great job teaching me where the icons were and what they meant. She did not teach me how to express myself with it.

For example, one particular day I was sent out of the classroom for drooling but really I had sneezed out some muffin. For the life of me, I couldn't find the words to say that I had just sneezed."





Communication Competence

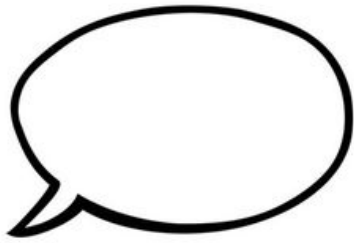
(Light, 1989)



COMMUNICATION BILL OF RIGHTS

9. The right to refuse or reject undesired objects, events, **actions** or choices.

9. The right to access interventions and supports that improve communication



"I loathe PICU. I actually call it Azkaban, and I've named my least favourite intensive Voldemort. I hate it there because it's so grim.

They always talk about me in front of me like I'm not there. I want to yell I can understand!

The worst part is the scary shit they talk about like worst case scenario stuff. I'm kind of used to it now, but it scared the crap out of me the first time."



Psychological Trauma

Psychological trauma is the unique individual experience of an event or enduring conditions, in which:

- The individual's ability to integrate his/her emotional experience is overwhelmed, or
- The individual experiences (subjectively) a threat to life, bodily integrity, or sanity

(Pearlman & Saakvitne, 1995, p. 60)

COMMUNICATION BILL OF RIGHTS

14. The right to be addressed directly and not be spoken for or talked about in the third person while present.





we went in a little doctor's office And see three people.

First person was my back Dr., second person was the kid helper. They told me and my mom that we need add guardianship for me. I was afraid about my future without mom. The family workers said mom had to go to the court to get the papers

[...thinking John Hancock, John Hancock... tries a few other things... we can't find the words in her device. So she reverts to trying to spell it.]

Signed.

I thought yes [she looked at me and wiggles her body - she obviously didn't mean that last word] I thought why do mom changed my last name to Hannah to be done with it.

[We are confused by what she means and asks her to tell us]

I am going to be all hers. I want to it. Hansen.



For years I was trying and trying and trying to tell it to mom. My dad is crazy and not a family Guy."

13 years I had a puzzle.

For 13 years I was a puzzle to my mom—with a song.

For 13 years I want mom to hear a piece of the song.



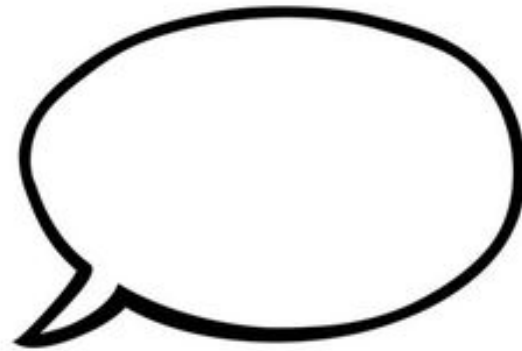
Language Development

It's harder for children with language difficulties to talk through their thoughts and feelings, harder for them to interact with others and to solve problems or to understand the subtle social rules of interaction.

COMMUNICATION BILL OF RIGHTS

7. The right to ask for and give information, including information **about changes** in routine and environment.
8. The right to be informed about people and **events in one's life**.

These few stories are from
those who have the means to
tell us...



What about those who cannot?







Narrative Skills

"Through narratives, we make meaning by telling and retelling stories about ourselves that both refigure the past and create purpose in the present and the future. Through narratives, we imbue personal meaning to our experience and are able to share ourselves with others... Through narratives, we make connections, heal profound wounds and develop a sense of who we are in relation to our own experiences.."

Soto & Starowicz, 2016, p. 142





Communication takes TIME





Counselling Services

- Often we don't even recognize that counseling is warranted/needed.
- Lack of counselors trained in AAC or communication supports for children and youth to access counseling services



Access to
Counseling
Services



Communication Intermediaries



COMMUNICATION DISABILITIES ACCESS CANADA

Accessibility Includes Communication

[ABOUT US](#)

[RESOURCES](#)

[REPORTS](#)

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[NEWS](#)

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[Home](#) > [Resources](#) >

Access to Justice / Communication Intermediaries

[About](#)

[Education](#)

[Resources](#)

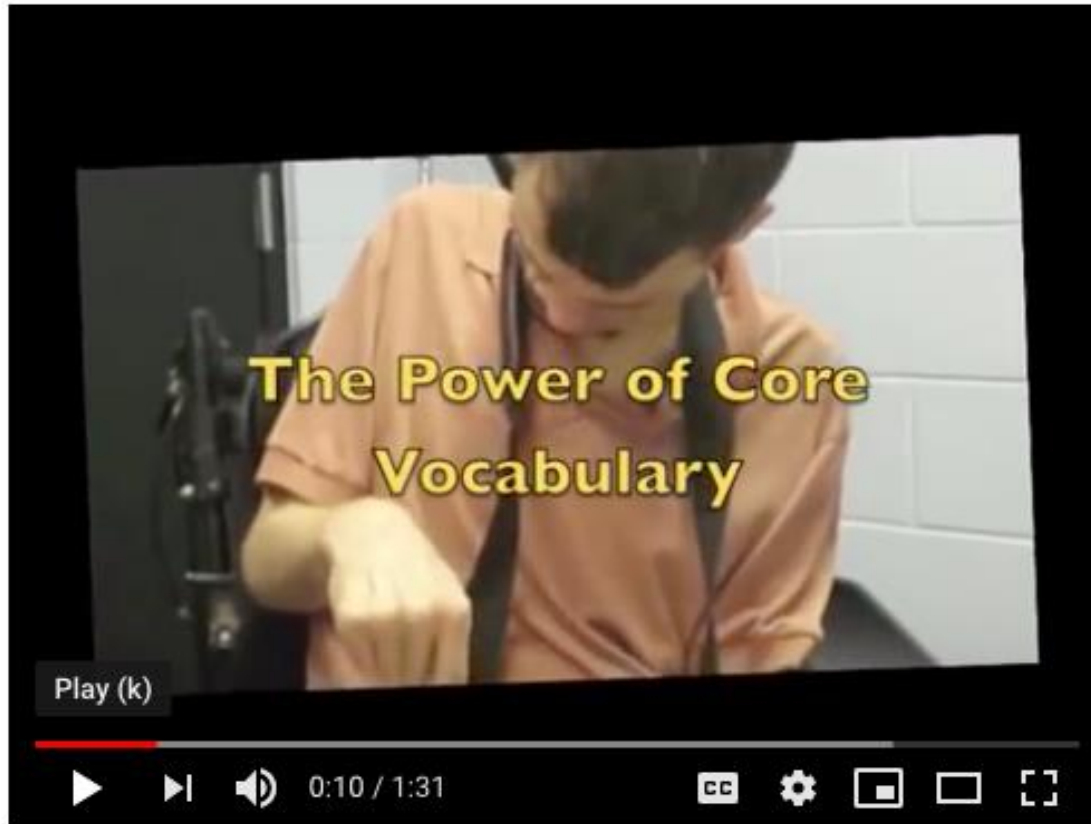
[Communication Intermediary Database](#)

Communication intermediaries assist victims, witnesses and accused communicating in police, legal and justice situations.

As funding permits, CDAC provides training and educational resources for communication intermediaries, police, legal and justice professionals and maintains a national communication intermediary database.



A life saving example



The Power of Core Vocabulary: Life Saving!

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



The Importance of Safe, Inclusive Spaces



Practice saying...



SOMETHING
WORTH
READING



Are we teaching our kids with intellectual disabilities to be more compliant than typical kids?

Or are we actively teaching them to stand up for themselves, to assert their wills, however inconvenient for those who serve as caregivers?

<https://starinhereye.wordpress.com/2018/01/08/we-need-to-talk-about-these-metoos/>

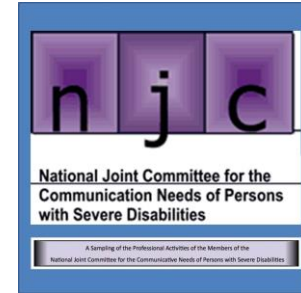
More to talk about!



<https://www.listennotes.com/podcasts/talking-with-tech/rebecca-moles-how-aac-can-8sFHcCeZyzT/>

Resources that may help

- Communication Bill of Rights!
- CEC's Policy on the Prevention and Response to Maltreatment



- Access to Justice/Communication Intermediaries



COMMUNICATION DISABILITIES ACCESS CANADA
Accessibility Includes Communication

<https://www.cdacanada.com/resources/access-to-justice-communication-intermediaries/>

Thank You!



Kathy Howery, PhD
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SAVE THE DATE! June 4, 2019, 6:00 PM Eastern

Dave Banes and E.A. Draffan, Global Systems: Design and Use of Symbols that Reflect Local Language and Culture

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Please consider joining USSAAC! Check out <https://ussaac.org/membership/> for benefits!



ISAAC is excited to announce that the 19th Biennial Conference of the International Society for Augmentative and Alternative Communication, **ISAAC 2020**, will be held on the **RIVIERA MAYA, QUINTANA ROO, MEXICO**.

AUGUST 1-2

AAC Camp, Pre-Conference Workshops, Executive and Council Meetings

AUGUST 3-6

Main Conference, Riviera Maya, Quintana Roo, Mexico

JOIN US for AAC events and perspectives, the latest in research and clinical innovations, workshops, seminars, exhibits, social events, entertainment - everything you have come to expect from an ISAAC conference, and more!

Mark your calendar today, and save the date for ISAAC 2020 in Mexico!

For more information, visit us at www.isaac-online.org and follow **#ISAAC2020** on Twitter.

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International Society for
Augmentative and Alternative Communication

www.isaac-online.org