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The Communicator

A Publication of the Autism National Committee

Introduction

We hope you enjoy our summer newsletter, which is packed with articles, poems, and information. There is a letter from the President that highlights the importance of the movie, Spellers. In New and Exciting, you will find a ground-breaking article on how touch may reduce cognitive load during assisted typing, as well as new books, information on conference and webinar recordings and much more. Also included in the newsletter is the updated and broadened version of the Autism National Committee Position Paper: Right to Communication for People with Limited or No Speech. There are poems by autistic writers, our Resources column, and a memorial tribute to Rosemary Crossley, founder of facilitated communication training. We are excited about our upcoming webinar, “A Very Sibling Thing: Growing Up with an Autistic Sibling.” We hope you will join us for this webinar and share the information with any interested parties.

In This Issue

Words

By Meaghan Buckley

I can recall written words but my auditory memory is limited to rehearsed phrases. The word piles are different. I think in your language but I verbalize in rote responses.

You see my brain has no problem with words and grammar. If language processing stopped at the thought level, I would get an A plus. The breakdown happens when it comes to combining words with sound, motor with sensory.

Words have always had a special appeal to me. Early in my life I taught myself to read words and to understand them. When I hear words they appear in my brain as spelled out language.

I can hear all the conversations in a room all at once. Everything I hear feels like fat noise bubbles that are sitting at the top of my brain. I can read them and type them but I can not add them to my speech.

My brain is full of piles and piles of words piled up on each other. Written words.

I want to talk but the words are stuck inside my head. It is difficult to separate them out and make sense of them, much less add sound to them.

When I type, the words flow easily. For me typing is a natural means of expression, kind of like your voice is for you.

Meaghan Buckley
Excerpt from The Meaghan Report
https://www.plrcontentsource.com/meaghan-report

Meaghan Buckley is a 38 year old autistic writer. She is the role model for the character Anna in the book, imPossible Dream, which she co-wrote with her mother, Gail. The book is available on Amazon and all other bookstores. Meaghan's family did not discover her remarkable intelligence and ability to express her thoughts through typing until she was 29 years old. Since then, she has given presentations at several local colleges, Boston University and Leslie College and at the 2019 AutCom Conference. Meaghan lived at home, attending Boston Higashi School, until she turned 21. She now lives in a group home with four other autistics.

Paper Words

By Judy Endow

Paper words
can be heard;
so speak up ink
and say them!

Speaking words
are burdensome;
they get her
lost   and tangled.

So,   pen and ink
are her first choice
to voice
what she’s not saying.

When speaking,   words
two people should
take their turns
to say them.

Start words   now
then stop   and wait
and listen   some:
adds up to conversation.

But,   starting words
and   stopping them;
then,   hearing words
and   seeing faces

is much   too much
to keep track   of
when having
conversation.

So,   paper words
are much preferred.
Speak up ink;
now say them!

Listen people
to the ink;
you won’t get
lost or   tangled!

- Judy Endow, MSW, LCSW; autistic social worker, poet, artist, and author. From *Making Lemonade: Hints for Autism’s Helpers*. For books, blogs, and art: JudyEndow.com.

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A Message from the President of AutCom

Lisa Keller

As I write this, New England has been experiencing an unusually soggy summer so far. In addition, this Spring and Summer has seen a tsunami heading toward us in the form of the growing support for and the increasing numbers of people who spell and type to communicate. *Spellers* (the movie) has busted the myth that autism and cognitive delay are synonymous, and more and more parents are at last starting to fight back against long-recommended treatment recommendations that favored taking a speech-only approach rather than embracing other ways to communicate.

As a speech-language pathologist, I have always felt that trying to force someone to produce sounds that their bodies could not form was seriously misguided and unproductive. Likewise, asking them to navigate their ways around complex symbol-based speech devices that sometimes required actually learning a new language of symbols, was unnecessary and a waste of their time and energy. Giving a person 26 letters (or more, depending on your nationality) and a space bar allows a person to say anything they want. And, it looks like a much easier--more direct and understandable—approach to take, while asking them to look and point. It looks and sounds simple, and doable. (It's more complicated than that, to be honest, and one needs good training on whatever approach one uses, of course.) More and more parents and educators are realizing that they can do this and that students can truly be successful. I've been fighting an uphill battle for years trying to get this point across, when along comes "Underestimated" (the book) and "*Spellers*," and it's taking the world by storm. AutCom sponsored a free screening of the film in Concord, NH on July 19, and other organizations have been doing the same all across the nation. The overarching message is one of hope and agency: presume competence in all autistics. When people gain a voice, they tell us that they know more than they could let us know before.

So it is fitting that, in this time of year when we celebrate our independence as a nation, many individuals who have longed for the freedom to express themselves more clearly are now doing so by spelling and typing their communication. It is my fervent hope that someday soon, schools will welcome and support students using whatever method of communication the students choose and prefer, with staff who can teach and support all methods.

Regarding AutCom policies, members of our Board have spent considerable time amending our Position Statement on Facilitated Communication, to update and broaden it. The new document, which replaces it, is a Position Statement on the Right to Communicate for People with Limited or No Speech. It focuses on the right to communicate using one's chosen methods, including approaches that use pointing, spelling, and typing, such as Rapid Prompting Method (RPM), Spelling to Communicate (S2C), and similar methods. I am proud of what they produced. Please review it at your convenience. I believe it should guide everyone.

Finally, a word about one of my personal mentors: Rosemary Crossley, whom many of us knew as Rosie. She was an educator in Australia who pioneered Facilitated Communication Training, beginning with a young girl with cerebral palsy living in an institution. Anne McDonald's story was the focus of a book that she and Anne wrote together called Annie's Coming Out, which I read in 1990. The most astounding idea in the book was not the actual method they used (which over time became distorted and controversial) but the concept of looking beneath the exterior and seeing the person inside. The idea of unlocking voices was what initially drew me to Speech Pathology, and I was beginning to despair in my profession until I read Rosie's book. It lit a fire under me, and all these years later, I still work to unlock those voices.

Rosie and I crossed paths many times, in person and by phone, and she was always tireless and patient with me as I asked (now obvious to me) what could have seemed silly questions. She guided me through my research study, and beyond. The last time I saw her was at a conference in Maryland in November of 2016, where she had me sequestered in her hotel room late at night while she uploaded several videos of her own research onto my laptop. She was forever generous with her time, knowledge, and advice.

Rosie died May 10, 2023 in Australia. Through her efforts, she gave hope and a voice to thousands, if not millions, of silent, disenfranchised individuals. Many of us miss her wisdom and humor, and we hope that we thanked her enough while she was with us.

We Applaud . . .

We applaud the Medical Student Section of the American Medical Association (AMA) House of Delegates for proposing Resolution 706 at the June 2023 Convention. The resolution has not yet been adopted (despite rumors on social media to the contrary). This Resolution, as amended, would change the current wording, which is "Our AMA support coverage and reimbursement for evidence-based treatment of services for Autism Spectrum Disorder including, but not limited to, Applied Behavior Analysis Therapy." The proposed revised wording would be "Our AMA support coverage and reimbursement for evidence-based services for Autism Spectrum."

The resolution, as originally written, included excellent points that have been made by autistics about harms of ABA, and it sparked much discussion at the convention and beyond. We hope that this will soon result in a lasting change and broadening in the AMA position regarding services for autistics, by acknowledging that other practices have much to offer, without risk of trauma to the participants. We are glad that autistics are increasingly being heard by medical students and others, and that the proposed resolution has opened an important discussion within the AMA. We hope the ripples will build into a much needed tidal change there and elsewhere.

The resolution and the edits are in the Reference Committee G Report (see link below), which states that it is a preliminary report and does not reflect official policy of the AMA. https://www.ama-assn.org/system/files/a23-refcomm-g-annotated.pdf

We also applaud these parents in the Netherlands: Parents call for action on controversial autism therapy ABA. “Parents of children with autism are calling on the government to ban a controversial treatment known as ABA… So far 2,500 parents have signed a petition calling for action and the LBVSO, an organisation for children in special education, says it has received 450 complaints about the programme.” Dutch News, May 25, 2023. https://www.dutchnews.nl/2023/05/parents-call-for-action-on-controversial-autism-therapy-aba/

New and Exciting

Tool Kit

The Words We Use: CommunicationFIRST’s Style Guide. July 11, 2023. Plain language version, short version, and 11-page downloadable pdf. “What follows is CommunicationFIRST’s own style guide, not a directive for others to follow. . . We are finding our own voice, telling our own truths, and expressing our own individual and collective stories. We are naming ourselves. And we choose our words with great care. This document explains our reasoning behind the words we currently choose to use and avoid.” https://communicationfirst.org/the-words-we-use/
Plain language version:https://communicationfirst.org/words-we-use-plain-language-version/ Short version: https://communicationfirst.org/the-words-we-use-short-version/

Articles

How Black autistic women and girls are excluded from conversations on resources and research. “Even with the billions of dollars the government has invested into autism-related research, there still is a lack of understanding and data on Black autistic women and girl https://19thnews.org/2023/06/black-women-and-girls-autism-data/

A Note to Parents. By Amy Sequenzia, August 8, 2023. “This essay is to call in those parents and caregivers who are not only real allies, but our lifelines. . . To those parents, to those caregivers I say: I know what you do, I know it can be hard, I see you.”

https://awnnetwork.org/a-note-to-parents/

The time is ripe for the renaissance of autism treatments: evidence from clinical practitioners. By Elizabeth B. Torres, Goldie Twerski, Hannah Varkey, Richa Rai, Mona Elsayed, Miriam Tirtza Katz, Jillian Tarlowe. Frontiers in Integrated Neuroscience, August 4, 2023. https://www.frontiersin.org/articles/10.3389/fnint.2023.1229110/full

Touch may reduce cognitive load during assisted typing by individuals with developmental disabilities. "This is the first theoretical framework for understanding how a facilitator's touch may assist individuals with DD to contribute linguistic content during touch-assisted typing." Frontiers in Integrative Neuroscience, Volume 17, August 3, 2023. Giovanni Nicoli, Giulia Pavon, Andrew Grayson, Anne Emerson, Suvobrata Mitra (peer reviewed, open access)

https://www.frontiersin.org/articles/10.3389/fnint.2023.1181025/full

Books

The Autistic Boy in the Unruly Body by Gregory C. Tino

https://www.amazon.com/Autistic-Boy-Unruly-Body-Autism/dp/B0B7XF3CVT

I Never Get Lost in the Woods by Aaron Jepson. Debut novel.

https://aaronjepson.com/

The Person Who Arrives: Connecting Disability Studies and Educational Practice for Teachers, Parents, and Others by Leah M. Kelley, Ed.D.,

https://www.amazon.com/Person-Who-Arrives-Connecting-Educational/dp/0228883652

Planning Your Career Through Intense Interests: A Guide for Autistic People by Yenn Purkis and Barb Cook

https://us.jkp.com/products/planning-your-career-through-intense-interests

Supporting Autistic Girls and Gender Diverse Youth. Foreword by Katie Koullas, CEO, Yellow Ladybugs; Written entirely by neurodivergent authors.

https://www.yellowladybugs.com.au/Document/Books

Spellbound: The Voices of the Silent - A collection of poetry, songs, stories and more by nonspeakers. Edited by Judy Hope Chinitz. https://www.amazon.com/Spellbound-Voices-Silent-Judy-Chinitz-ebook/dp/B0C31R8B65

Talking Fingers: Voices Of Indian Non-Speaking Autistics - Embrace and Celebrate Neurodiversity and All Communication Styles. Edited by Padma Jyothi and Chitra Paul. "WITHOUT A VOICE LIFE IS A WASTELAND. SURROUNDED BY A LOVING FAMILY AND EVERY COMFORT, IT IS STILL A WASTELAND." - Chandima Rajapatirana https://www.amazon.com/Talking-Fingers-Voices-Non-Speaking-Autistics/dp/819585401X

Tressing Motions at the Edge of Mistakes: Poems by Imane Boukaila

https://milkweed.org/book/tressing-motions-at-the-edge-of-mistakes

Conference and Webinar Recordings

Rethinking Autism for the Twenty-First Century Conference: Leveraging Science, Technology, Engineering, and Mathematics. Launching RU-ACE. Rutgers University Certificate of Excellence. Presented by New Jersey Autism Center of Excellence (NJACE). Recording of conference speaker presentations (17 videos of conference talks and events; captioned; slides and transcripts available for some presentations). Presenters: Prof. Elizabeth Torres, Elizabeth Rosenzweig, Dr. Eric London, Prof. Jonathan Delafield-Butt, Dr. Eilat Almagor, Anat Baniel, Christopher Dudick, Dr. John Summers, Prof. Vikram Jaswal, Elizabeth Vosseller and Ian Nordling, Dr. Susan Crawford, Prof. Damian Zanotto, Elizabeth Horn.

https://sensorymotorintegrationlab.com/njace-conference/

Vikram Jaswal: Community support and cognitive science help flourish non-speaking autistics (29:32)

https://m.youtube.com/watch?v=KyWoWfUC0zw&noapp=1&mibextid=Zxz2cZ

Events:

I-ASC (International Association for Spelling as Communication) holds online events including Neurolyrical Café (last Friday of every month), Spellers and Allies Meeting (monthly), Boards and Chords, Spell X, Motormorphosis (annual conference), and more. Check the link for more information.

https://i-asc.org/events/

Political Action

Casey, Dingell Introduce Bill to Provide Historic, Permanent Investment in Home Care for Seniors and People with Disabilities. The Better Care Better Jobs Act would expand access to long-term care, enabling older adults, and people with disabilities to receive quality care and remain in their communities.

https://www.casey.senate.gov/news/releases/casey-dingell-introduce-bill-to-provide-historic-permanent-investment-in-home-care-for-seniors-and-people-with-disabilities

MY NEMESIS

By Sujit Kurup

Calmness before a storm
So my mind eases to all seething chaos
Bringing erupting out forth daring anger
Vividly appearing to rear head me off
balance.

Gave a task to complete
Keeping my sane mind to contemplate
The angry mind is masking my true self
Basking in the cool victory

Clearly that is not appearance
Soothing the frayed needed tempers
Calling out to my inner serenity.

Diving into the great watch of striving tumble
Into eased gorge of steady nuances
Must have to seek freed chaos

Meeting with my nemesis.

Anger treads with fear
Darting each step to caving into seething ache
Say when does the dreary dose of the twain be
undone
Nesting in each other’s arms

Caring does really greet with dear sanity
Saving my mind from death to eternity.

Neither here nor there
Very dear to my escape from reality
Hanging in limbo
lost to reality of time and space
What are the changes so unexpected
Forever as revealed by surrealness
Wishing in hidden aspirations
Daring to bare Inner apprehensions

My seen and paused somber state
Sujit Kurup

Sujit Kurup is a social and warm person by nature who loves the outdoors. He writes poetry, does abstract paintings, and has a degree in Business Administration from Suny College, NY. He is currently the new treasurer of AUTCOM.

In Memoriam
Dr. Rosemary Crossley

Rosemary Crossley and Annie McDonald

Dr. Rosemary Crossley, AM, PhD, died on May 10, 2023. She was 78 years old. She became famous as a therapist with and advocate for people with little or no functional speech.

Crossley was born on June 5, 1945 at Horsham. She was educated at Morongo school and went on to the Australian National University. After a brief period in the Australian Public Service she began working at the Victorian Spastic Centre with people with severe handicaps.

In 1974 she was hired as a playleader at St. Nicholas Hospital, a Parkville institution for severely handicapped children run by the Victorian Health Commission. It was there that she met Anne McDonald. McDonald had severe cerebral palsy, could not walk, talk, or feed herself, and had been diagnosed as severely retarded.

Crossley decided to see if she could find a way for McDonald to communicate by pointing – first at choices on a communication board, then at word blocks, then letter blocks, and finally on a letter board.

This brought Crossley into conflict with her superiors at the hospital, and eventually McDonald asked to leave. The Health Commission refused to allow this, and were taken to the Victorian Supreme Court on a very rare habeas corpus action. Anne won the action, and left St. Nicholas to live with Crossley and her partner Chris Borthwick for the next thirty-two years.

“Annie’s Coming Out”, Crossley and McDonald’s account of their struggle, was an international bestseller and went on many school curriculums. It was later made into a movie of the same name, which won the AFI Best Picture award in 1984.

The court case, the book, and the film exposed the shortcomings of St. Nicholas Hospital and of the system that had created it, and led directly to the closure of the hospital a few years later – the first step in the deinstitutionalisation of care for people with disabilities in Victoria.

In 1986 Crossley founded the DEAL Communication Centre in Caulfield. The Centre began by working mainly with people with cerebral palsy, but soon found itself taking on clients with other diagnoses – Down Syndrome, Rett Syndrome, developmental disabilities, and, increasingly, autism. In case after case Crossley was able to establish a means of communication with the client, demonstrating that their diagnoses of intellectual disability had been made in error.

Crossley described her methods as Facilitated Communication Training, involving coactive hand-on-hand movement at the beginning of the training process. While she always aimed for eventual independent communication, the method was criticized for allowing communicators to impose their messages on their partners. Nonetheless, many people who Crossley had helped communicate went on to graduate from schools and universities.

When Anne McDonald died in 2010 DEAL changed its name to the Anne McDonald Centre, but the work went on. iPads, in particular, have spread hand-pointing skills more widely, and newer clients were better able to communicate more independently sooner.

Crossley wrote books (including “Speechless”, 1997) lectured at universities and presented papers at conferences around the world. She was awarded an AM in 1986 for services to people with severe communication impairments and took a doctorate in communication from Victoria University in 1998. She was admired for her indomitable spirit, her determination, and her ability to empower others in advocating for themselves and for the people they loved.

Dr. Crossley died of cancer in the Royal Melbourne Hospital on 10/5/2023. She was working till the end: in the hospital, she was able to assist a nurse who had a foster son with communication handicap with books, boards, and iPad apps. Together, Crossley and McDonald changed the history of disability. Crossley’s life work of teaching, researching, and advocating for people with little or no functional speech has improved the lives of thousands of the most vulnerable people in many countries and over five decades. Her sharp intellect and wicked good humour will be missed. The world has lost an important voice speaking out for the rights of people with disabilities.

The above information was taken primarily from a press release from the DEAL Communication Center in Melbourne, Australia with permission from Chris Borthwick.

Memories of Rosemary Crossley

Harvey Lavoy and Tracy Thresher

Tracy Thresher: I am very sad to hear that Rosemary Crossley passed away. It’s hard to imagine the world with her sense of humor and relentless work to support non-speaking people. I would not be the person I am today if Rosemary did not discover supported typing. We will mis you Rosie and thank you for all you did.

Jamie Burke: I well now understand Rosie's knowing how to incur successful placing of thought realities on the keyboard. In the beginning, I was feeling the fear of knowing she understood my anger and my fear of what would be expected of me as I vitally revealed my soul in life.

I was a bit scared of her, but I was also importantly communicating with her silent encouragement of passion of proving people to be wrong. She understood everyone was being placed in the suggestion of being given real opportunities, but not being given the belief. Rosie did love the challenge of supplying vital emotional encouragement, and I still am able to hear her voice with strong volume, sounding perhaps like a tough taskmistress of communication.

I am dearly loving her memories of my tender years but now I am truly successful in typing and speaking. Rosie took my hope and my fear and sailed me off in to the complicated world of typical. Grateful forever and for everything.

Love,
Jamie Burke, Syracuse, New York

Darlene Hanson: Rosie changed my life and the lives of so many others. She constantly reminded us to look to the person. As the support person my responsibility is to support the person to be all they can and want to be. Thank you Rosie!

Kris and Rosie

Kristofor Medina: I first met Rosemary Crossley at Syracuse New York University in 1989 when I was only seven years old. Alan Kurtz from Washington County Mental Health introduced me to Facilitated Communication when I was in second grade. I was so excited. We were fortunate to continue our friendship over the years at many conferences in the United States and Canada.

I was fully included with my same age peers throughout my elementary, middle school, and high school in Barre, Vermont. I graduated from high school with Honors and was accepted at the University of Vermont with an academic scholarship. It took me eight years, taking two classes per semester as a part-time student commuting to complete my Bachelor's Degree. I presented at conferences and am active at the Vermont Legislature testifying for the rights of all people with disabilities. I have written articles, provided training, and am a staff member for Green Mountain Self Advocates in Montpelier, Vermont.

Thanks to Rosemary Crossley, I and so many others whose life was changed when they found their voice through Facilitated Communication. Thank you Doug Biklen for bringing Rosemary to Syracuse and Vermont from Australia.

Jim Mondro: Crossley helped me learn to communicate. When she brought a Lightwriter to Syracuse, i asked her to make it speak not Australian but American.

Pascal Cheng: My first introduction to Rosemary Crossley's work happened in early 1991 when a friend handed me an article written by Professor Doug Biklen from Syracuse University and published in the August 1990 issue of the Harvard Educational Review journal. The article was entitled "Communication Unbound: Autism and Praxis" and described the work that Rosemary Crossley was doing with a new method of communication called facilitated communication with non-speaking individuals at her communication center in Melbourne, Australia. Reading that article and learning about Rosemary's work had a profound impact on the direction my work journey would take from that moment on. Over the years, I had the opportunity to hear Rosemary speak at different conferences and observe her working with different people. In our Wellspring Guild training programs for coaches and trainers in FC, we talk about having a "toolbox" of resources, written materials, and equipment to use when doing training and coaching. Rosemary probably had the most expansive toolbox of anyone that I have ever met in the field of communication. And this was a toolbox of not just low tech and high-tech communication boards and devices, but also a wealth of knowledge built upon many years of experience working with a variety of communicators. And she carried this "toolbox" with an incredible spirit and belief that anyone could learn to communicate with the right support.

Char Brandl: I wish I could remember just when I first heard the name Rosemary Crossley. It is hard to convey just how much she impacted me in my life and especially in my career. Wanting to get some of the facts straight before I started writing my thoughts, I did a quick Google search and saw that she was identified there as a “writer” - well, sure, but she was so much more. Her book, “Annie’s Coming Out” and the movie based on the book, “Test of Love,” created a sea change in the thinking about people with significant disabilities.

Like Rosie, in the mid-1970’s I was working with children who were considered to be severely or profoundly intellectually disabled (not exactly the terms we were using back then). These kids were entering the public school system here in the U.S. for the first time because the law now said that ALL children were entitled to a free and appropriate education. I was one of the first in my state to be trained and certified as a special education teacher, but I would also be the first to admit I had no idea just how to provide such an education for kids who were unable to speak and/or unable to walk, feed themselves, etc. Truthfully, no one knew. But I found myself immediately drawn to them, and had a motherly instinct to make life at school as comfortable and meaningful to them as possible.

Rosie was way ahead of all of us, determined to find a way for her “special” student, Anne McDonald, to communicate her needs - and ultimately so much more. Rosie led the way, through some extremely challenging times, standing up to the skeptics, taking Anne into her own home, changing Anne’s life and the lives of countless others over the years.

I read the book, I saw the movie, I listened to Rosie at one conference after another, and because of her I have been supporting non-speakers using Facilitated Communication ever since. I faced much of the same skepticism and criticism along the way, but it was Rosie’s strong example and steadfast belief in these misunderstood and underestimated young people that kept me going. I am forever indebted to her as a mentor and a true source of inspiration.

Char Brandl,
Retired teacher, still actively supporting some amazing typers

Rita Rubin: After many years of friendship with Rosie, she apologized to me for thinking I was “an airhead” when we first met. That friendship came from our common goal of wanting as many non and limited verbal people to enjoy the life that she made possible for our daughter Sue – an inclusive education, a college degree, a small business, and the ability to advocate for herself and others. Rosie changed all of the lives of the Rubin family and beyond.

Bob Rubin: Rosie was a presenter at facilitated communications symposia in Whittier quite a few times, and she stayed at our home on those occasions. Typically, we had a get-together at our house for the dozen or so symposium speakers and coordinators each time. Rosie always pitched in, helping in many ways to get things ready for our guests.. So when people asked us if we knew Rosemary Crossley, we would reply: "Sure, she cleaned our bathroom!"

Rita Rubin, Sue Rubin, Emily Neimeyer, Rosemary Crossley and Anne McDonald

Alan Kurtz: When I first heard Rosie speak in Syracuse, I was struck by her apparent ability to convey high expectations to the people she supported. I returned to Vermont, committed to demonstrating higher expectations myself. So, I tried adopting what I thought was a Rosemary Crossley approach in working with the first person with whom I had tried supported typing. Up to that point, he had typed mostly “echoed” responses – TV stations, radio stations, TV programs and product names. I sat down next to him and, doing my best to channel Rosie, said something like: “You are very smart and you have a lot to say, but it is just a waste of my time and your time if you are just going to type the names of radio and television stations. If you are really going to share what you want and what you are thinking, you are going to have to start typing sentences.” He began typing meaningful sentences immediately. Of course, I was absolutely stunned, but I had to act as though this was exactly what I expected. It was at that point I learned from Rosemary Crossley exactly what it meant to have truly high expectations.

Sandi McClennen: Rosemary Crossley changed the world. We now know without a doubt that nonspeakers are intelligent and want to communicate. And we know how to give them access to communication. Thousands of autistics and people with other communication-related challenges from all over the world and their parents and friends will be forever grateful to her, and tens of thousands in the future will benefit from her pioneering work. Rosemary Crossley, may you rest in peace. You have done so much for so many.

In Memoriam
Donald Grey Triplett

First child diagnosed as autistic.

September 8, 1933 – June 15, 2023

Donald Grey Triplett's life is one that we heartfully acknowledge and celebrate, as it established an expectation for inclusive living for autistic and disabled people everywhere. His community of Forest, Mississippi, loved him, supported him, and accepted him. He lived in an inclusive environment and was not just an accepted member of the community: he was part of the fabric of the town.

Yet, Donald began life as an exceptionally withdrawn child, who gave the appearance that he lacked interest in other children, and while he spoke, he would repeat select words or phrases over and over. However, he exhibited a remarkable memory, could sing songs after hearing them once, and showed a proclivity for counting and measuring. (bbc.com, 1/21/2016, Donald Grey Triplett: the first boy diagnosed as autistic; cbsnews.com>miami 6/17/2023, Donald Triplett, the first person diagnosed with autism, dies at 89)

In 1938, his parents, believing him to be intelligent and capable, but feeling unable to reach him, took him to be examined by Dr. Leo Kanner, an Austrian child psychiatrist. Kanner was unable to diagnose him with the criteria of the time, but by 1943, Kanner discovered ten more cases that were similar to Donald's and published an article titled, *Autistic Disturbances of Affective Contact*. In that paper, Triplett was noted as Case 1, Donald T. He was the first child to be diagnosed as autistic. (bbc.com, 21January2016, Donald Grey Triplett: The first boy diagnosed as autistic)

Donald attended Forest High School and went on to graduate from Millsaps College with a bachelor's degree in French. After earning his degree, he returned home to Forest, Mississippi, where, though he continued throughout his life to repeat certain words, assign numbers to people he knew, have difficulty elaborating or making explanations, and so forth, he also worked for his family's bank for nearly 65 years. He also played golf, learned to drive, had friends, attended the Presbyterian church and traveled extensively, including overseas. (nola.com, 6/15/2023, Don Triplett, autism Case 1 and the longest living known person with autism, dies)

"I'm proud to be a native of Forest," Donald declared in a rare interview. And the town of Forest was proud to count him among their own. (usatoday.com,11/14/2022, Interview, Forest man first person diagnosed with autism) We hope that someday that, like Forest, all communities will be welcoming places for each and every member.

Resources

Communication

Annie's Coming Out by Rosemary Crossley and Anne McDonald. Available to read free online in the Internet Archive.
https://archive.org/details/anniescomingout00cros

Annie's Coming Out (1984), also known as *A Test of Love*, is a feature-length movie (based on the book by Rosemary Crossley and Anne McDonald). (1:29:08; captioned) It is available free to watch online in the Internet Archive.
https://archive.org/details/annies-coming-out-1984

Speechless by Rosemary Crossley – Available to read free in the Internet Archive.
https://archive.org/details/speechlessfacili00cros/mode/2up (Hardcopies available from Alan Kurtz – kurtz@maine.edu)

Vikram Jaswal: Community support and cognitive science help flourish non-speaking autistics (29:32)
https://m.youtube.com/watch?v=KyWoWfUC0zw&noapp=1&mibextid=Zxz2cZ

Toolkits

ASAN has released two important resources together as a part of their Proud and Supported Series. Both are available in Easy Read and plain language formats.

- A Self-Advocate's Guide to Safer Sex and What Do I Need to Know About Sexual Assault? https://autisticadvocacy.org/resources/proud/
- For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions by ASAN https://autisticadvocacy.org/policy/briefs/intervention-ethics/

HCBS (Home and Community Based Services) Settings Rules Resources by ASAN

https://autisticadvocacy.org/policy/toolkits/hcbsrule-2/

Supported Decision-Making Toolkit. Supported decision-making is an alternative to guardianship. The toolkit includes information, handouts, and worksheets and forms one can fill out, print, and use. Download the toolkit: https://bit.ly/3J0bM9f

Report on Autism Diagnosis Data

ASAN Statement on Updated Autism Diagnosis Numbers, March 23, 2023. "ADDM (The Autism and Developmental Disabilities Monitoring Network) is a program funded by CDC to collect data to better understand the number and characteristics of children with ASD and other disabilities living in different areas of the United States. Their goals are to describe the population of children with ASD; compare how common ASD is in different areas of the country; measure progress in early ASD identification; identify changes in ASD occurrence over time, and to understand the impact of ASD and related conditions in US communities." (cdc.gov)

In their latest findings from 2020 data, based on tracking from 11 US communities, the ADDM Network found 1 in 36 eight-year-olds were identified with ASD. While boys were still 4 times more likely to be diagnosed with ASD as girls, this was the first time ADDM Network found the percentage of girls identified to be over 1%. (cdc.gov)

For a more detailed synopsis of the ADDM report with commentary, see the ASAN Statement at this link.

https://autisticadvocacy.org/2023/03/asan-statement-on-updated-autism-diagnosis-numbers-2/

Free webinar: ***A Very Sibling Thing: Growing Up with an Autistic Sibling.*** A panel of siblings of autistics will respond to a series of questions posed by an autistic moderator and as time permits will respond to questions from attendees.

When: Saturday, November 4, 2023, 11:00am-1:00pm ET / 10:00am-12:00pm CT / 9:00-11:00am MT/ 8:00-10:00am PT. Registration in advance is required. Watch for more information on our Facebook page and via email, if you are on our mailing list!

AutCom
Autism National Committee
The first autism advocacy organization dedicated to
"Social Justice for All Autistics" through
a shared vision and a commitment
to positive approaches

Autism National Committee (AutCom) Position Paper

Right to Communicate for People with Limited or No Speech

It is the policy of Autism National Committee that everyone has something to say and a right to say it. People choosing to use any method of communication by typing, spelling or pointing must be given full consideration and respect. This includes people who do not speak or do not speak reliably, consistently, and effectively at all times.

This position paper includes approaches known as Supported Communication or Supported Typing, Typing to Communicate, Facilitated Communication Training (FCT), Rapid Prompting Method (RPM), and Spelling to Communicate (S2C). These and similar approaches with different names are accepted and valid ways in which autistics and others may learn to exercise their right to say what they have to say fully and effectively and to be heard.

“It is hard enough to live in silence without anybody or anything making it harder or more uncomfortable.” Sharisa Joy Kochmeister, Former AutCom President

PRINCIPLES:

1. **Communication is a right, not a privilege.**
2. All people have a right to communicate using their chosen method(s), and their communication must be heard and respected by others.
3. People with disabilities of all ages (including autistics) who do not communicate effectively, meaningfully, and consistently through speech must have an available means of communication that allows their fullest participation in the world. This includes access to a system that allows expression beyond wants and needs.
4. Children whose oral language is either absent or delayed for any reason must have access to any and all forms of communication that allow them to communicate meaningfully in age-appropriate ways by 18 months of age.

5. People using any method to communicate have an absolute right to access it, and people who do not have a full and effective means of communication have a right to the opportunity to explore one or more of these approaches. People who are denied access to whichever types of Augmentative and Alternative Communication (AAC) they choose are denied their basic rights because communication is the basis of all other rights and the means by which those rights can be realized.

6. Literacy must be taught to all students regardless of the apparent severity of their disability. This is particularly true for autistic students, whose complex movement, anxiety, connectivity, and sensory differences may preclude their demonstrating their abilities in conventional ways. However, the individual does not have to demonstrate literacy before being introduced to any of these approaches to communication. Demonstrated literacy is not a prerequisite.

7. It is essential to presume competence regarding each person's potential to learn. This is particularly true for autistics as well as those with other challenges involving communication. To be precise, cognitive potential should always be presumed to exist, and a rigorous, systematic, and long-term commitment is required in order to enable each person to have full and effective communication of their choice.

8. The primary goal of any approach to communication is always for individuals to achieve full and effective autonomous communication. However, given the complexity of challenges faced by individuals, total independence in communication and in demonstrating literacy may not be possible at all times and for every single person.

9. Anyone attempting to introduce any of the approaches that this position paper particularly addresses as a training process for communication must have a solid foundation of training in that method. Coaching and mentoring by experienced practitioners in these methods are essential parts of the learning process for new communication partners. Those who provide training to communication partners, the communication partners themselves, and spellers/typers require and must be provided on-going training, supervision, and support.

10. Additionally, communication partners must adhere to strict standards in order to minimize partner influence on spelled/typed messages (which AutCom acknowledges may occur) and to assure that all communication is generated and owned by the speller/typer. Intentionally guiding or prompting a speller/typer to a target in open responses or open communication is unacceptable under any and all circumstances.

11. As in speech, not everything a person types is what was intended or clear. Clarification is essential.

12. Funding must be available for communication partners, ongoing training, and the communication device(s) each individual requires to communicate fully and effectively.

13. People with disabilities who use multimodal or alternative forms of communication should be active and proactive at the local, state, national and global levels in shaping policies and practices of government agencies, professional organizations, and other entities that directly affect their lives. Spelling/typing methods for communication must be accepted in policy and practice as an equal choice among AAC opportunities.

14. Methods of spelling and typing for communication may involve multiple forms of support provided by the communication partner. This support will be highly individualized based on the specific, changing, and often fluid, needs of the speller/typer. Consequently, the process of spelling/typing does not look the same from person to person. There is a wide diversity of supports and styles of pointing to targets involved, and there is no single rote prescription of how to introduce or use such methods.

15. Pointing, spelling, or typing to communicate, and other forms of AAC, may reveal competencies, feelings, and thoughts that were previously unexpressed. We also affirm that all individuals possess unique gifts and strengths whether or not they need access to some type of support or educational method to allow them to communicate those gifts and strengths.

16. Communication partner influence is not an insurmountable obstacle to the responsible and dependable use of spelling and typing to communicate. Message-passing in everyday life (in which the speller/typer communicates information not known to the facilitator) is a straightforward way of verifying a message's validity.

17. AutCom asserts unequivocally that there is nothing mystical, magical, miraculous or mythical about communication by spelling/typing. Indeed, use of these approaches is very difficult and challenging work for spellers/typers and their communication partners.

"As for FC, it is a tool I use to get where I wish to go. Just as a voice is used by those who speak." – Jenn Seybert

Autism National Committee

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Principles of the Autism National Committee

As a member of the Autism National Committee, I endorse for all autistics and those with related disabilities the development of high-quality community services, including education, residences, jobs/job training programs, and of individualized support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communication and social needs; of adequate supports to every family to assist them in maintaining their family member with a disability in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individuals' behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

Join us on Facebook! **“Like”** and share all our perspectives far and wide.

https://www.facebook.com/autcom

Time to Renew or Join Today
Annual Membership Begins in January

AutCom Annual Membership Form

Join any time. Renew each January (except for Lifetime Members).

Name ____

Address ____

City __________________________________ State _____ Zipcode __________

Phone ___________________________________

Email ___________________________________

I want to _____ Renew my membership _____ Become a member

I am a/an _____ Autistic person _____ Family member _____ Friend

_____ Student _____ Professional (field) _____________________________

Enclosed is my membership fee of: _____ $10.00 (autistic person)

_____ $30.00 (regular membership) _____ $10.00 (student membership)

_____ $75.00 (supporting membership) _____ $500.00 (lifetime membership)

I am enclosing an additional $___________ donation to speed up the good work!
I want my donation to be ____ listed ____ anonymous.

Send this form or a copy and a check payable to Autism National Committee at

P.O. Box No. 82, 300 Cypress St., Liverpool, NY 13088-0082

AutCom Officers

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Time to Renew or Join Today!

Annual membership begins in January

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Membership form on Page 23

The Communicator

The COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to communicator@autcom.org

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